

# **Life-Sustaining Treatment**

**Making Decisions  
and  
Appointing a Health  
Care Agent**

**July 1987**

**The New York State Task Force  
on Life and the Law**

## Task Force Members

**David Axelrod, M.D., Chairman**

*Commissioner of Health, State of New York*

**Rev. Msgr. John A. Alesandro**

*Chancellor, Roman Catholic Diocese of Rockville Centre*

**Mario L. Baeza, Esq.**

*Member, Debevoise & Plimpton*

*Lecturer, Harvard Law School*

**The Right Rev. David Ball**

*Bishop, Episcopal Diocese of Albany*

**Rabbi J. David Bleich**

*Professor of Talmud, Yeshiva University*

*Professor of Jewish Law and Ethics,*

*Benjamin Cardozo School of Law*

**Evan Calkins, M.D.**

*Head, Division of Geriatrics*

*SUNY at Buffalo and Buffalo VAMC*

**Richard J. Concannon, Esq.**

*Kelley Drye & Warren*

**Myron W. Conovitz, M.D.**

*Attending Physician, North Shore Univ. Hospital Clinic. Assoc.*

*Prof. of Med., Cornell Univ. Med. College*

**Saul J. Farber, M.D.**

*Dean and Provost*

*Chairman, Department of Medicine*

*New York University School of Medicine*

**Alan R. Fleischman, M.D.**

*Director, Division of Neonatology*

*Albert Einstein College of Medicine, Montefiore Medical Center*

**Beatrix A. Hamburg, M.D.**

*Professor of Psychiatry and Pediatrics*

*Mt. Sinai School of Medicine*

**Helene L. Kaplan, Esq.**

*Webster & Sheffield*

*Chairman, Board of Trustees*

*The Carnegie Corporation*

**Rev. Msgr. Henry J. Mansell**  
*Vice-Chancellor for Priest Personnel*  
*Archdiocese of New York*

**Rev. Donald W. McKinney**  
*First Unitarian Church, Brooklyn*  
*President, Concern for Dying*

**Georgia L. McMurray, C.S.W.**  
*Deputy General Director*  
*Community Service Society of New York*

**Maria I. New, M.D.**  
*Chief, Department of Pediatrics*  
*New York Hospital—Cornell Medical Center*

**Ruth A. O'Brien, R.N.**  
*Assistant Professor of Nursing*  
*University of Rochester*

**John J. Regan, J.S.D.**  
*Professor of Law*  
*Hofstra University School of Law*

**Rabbi A. James Rudin**  
*National Director of Interreligious Affairs*  
*The American Jewish Committee*

**Rev. Betty Bone Schiess**  
*Episcopal Diocese of Central New York*

**Barbara Shack**  
*The New York Civil Liberties Union*

**Rev. Robert S. Smith**  
*Director, Chaplaincy Services*  
*Health Sciences Center, SUNY at Stony Brook*

**Elizabeth W. Stack**  
*Member, Syracuse Developmental Center Board of Visitors*

## Staff

Tracy E. Miller, J.D., *Executive Director*

Robert N. Swidler, M.A., J.D.

Irvine Brawer, M.A., C.S.W.

John Finck, M.A.

Elizabeth Peppe



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## **Preface**

In March 1985, Governor Cuomo convened the Task Force on Life and the Law. He asked the Task Force to develop recommendations for public policy on a range of issues arising from recent advances in medical technology: the determination of death, the withdrawal and withholding of life-sustaining treatment, the new reproductive technologies, the treatment of disabled newborns, organ transplantation and, in a more limited context, abortion. The Governor charged the Task Force to present its recommendations in the form of proposed legislation, suggested regulations or a report describing its conclusions.

In response to its mandate to study life-sustaining treatment, the Task Force first addressed the issuance of do-not-resuscitate (DNR) orders. It chose to do so because of the history of confusion and abuse in New York State associated with the orders. The Task Force identified two kinds of abuses in need of resolution: the issuance of orders without consent and the failure to issue orders when appropriate, which resulted in futile and highly intrusive treatment for some patients. Both kinds of decisions were often reached in an atmosphere of secrecy. The Task Force concluded that legislation was essential to clarify the rights and protections afforded patients, family members and health care professionals when decisions about resuscitation must be made. In July 1987, the New York State Legislature enacted a law embodying the Task Force's legislative proposal.

### **The Framework for Decisions About Life-Sustaining Treatment**

After completing its work on the resuscitation issue, the Task Force turned to questions surrounding decisions about life-sustaining treatment in general. The Task Force considered the clinical context and obstacles to informed decision-making by patients, as well as the rights patients now have under New York law. It studied the apparent gap between clinical practice and existing legal protections and examined the educational and legislative measures needed to enhance the decision-making process. It also deliberated at length about the ethical framework for decisions about life-sustaining treatment.



The consensus that emerged from these deliberations is set forth in Part I of this Report. The discussion addresses the clinical context, the right to refuse treatment under New York law and the ethical dilemmas associated with decisions to forego treatment.

The Task Force hopes that the consensus it has achieved on these issues will provide meaningful guidance to the public and policymakers. Its deliberations are one step in an ongoing dialogue within and among many different communities in the State: religious communities, health care professionals, lawyers, patient advocate groups and the general public. This Report aims both to stimulate discussion and to provide a framework for achieving a broad public consensus.

## **Proposed Legislation**

In the course of its deliberations about life-sustaining treatment, the Task Force concluded that there is a compelling need for legislation to ensure that a person's preferences about treatment are honored after the person has lost the capacity to make those preferences known. Such legislation would respond to the increasing anxiety many individuals feel about control over their treatment in the face of proliferating technologies available to prolong life. The legislation would also serve the interests of those involved in health care delivery and society as a whole, since the ethical dilemmas associated with decisions about life-sustaining treatment are greatly intensified when guidance from the patient is not available.

The second half of this Report describes a legislative proposal that would allow an adult to delegate authority to make health care decisions to another person and to express written wishes about treatment. This delegation and any instructions the individual provides would be set forth in a document called a "health care proxy."

The Task Force believes that legislation on the health care proxy is essential not only for decisions about life-sustaining treatment, but for other treatment decisions as well. At present, when a person loses decision-making capacity, the consent of family members is usually accepted without any clear legal authority to do so. When a patient has no available family members to provide consent, health care professionals must often seek judicial approval for treatment, no matter how beneficial the treatment or uncontroverted the patient's need. This process can be costly and cumbersome; it forces patients in need of

treatment to wait for judicial approval before treatment is provided. Although the Task Force's original mandate related only to life-sustaining treatment, it concluded that the health care proxy should protect the broader range of interests related to consent for treatment. It has designed its legislative proposal accordingly.

The Task Force's legislative proposal and a discussion of the related legal, ethical and policy issues are described in Part Two of this Report. While the deliberations described in Part One provide an ethical and legal framework for decisions about life-sustaining treatment, the legislation itself addresses only the issue it was designed to resolve—creation of a process to ensure that an individual's wishes about treatment will be followed after the individual loses the capacity to participate directly in treatment decisions.

The Task Force strongly believes that New York State must address the difficult dilemmas presented by new medical technologies developed to sustain life. It has devoted its efforts and energies to facilitating that process.

# **Executive Summary**

## **Summary of Part One: The Social, Legal and Ethical Context For Treatment Decisions**

The Task Force's conclusions and recommendations regarding the social, legal, and ethical issues related to decisions about life-sustaining treatment are summarized below. One Task Force member, J. David Bleich, submitted a minority statement with respect to several of these recommendations. That statement is included in the Report.

- The Task Force strongly believes that physicians must engage patients, including those who are severely or terminally ill, in a dialogue about treatment to foster their ability to make treatment decisions. This dialogue must be understood as a central part of the obligation of care owed to all patients.
- Physicians should provide patients with information about: their diagnosis; the available treatment alternatives and the associated risks and benefits; the prognosis following respective treatments; significant uncertainties in the evaluation of available treatments; and measures available to provide comfort and relief from pain.
- Health care professionals often focus on concerns about civil and criminal liability in responding to requests to forego life-sustaining measures. This assessment of potential liability must be squarely grounded in a responsible understanding of the law. Concerns about liability must also be balanced against respect for the patient's basic right to decide about treatment.
- Recent judicial decisions in New York and other states provide strong support for the right to refuse treatment and corresponding protection for health care providers when they act in accordance with the informed, voluntary choices of competent adults.
- A broad educational effort is essential to clarify misconceptions about the rights of patients to make decisions about their own health care and the legal obligations and protections afforded health care professionals.

- The Task Force urges lawyers and administrators for health care facilities to create a process by which medical professionals can be educated and advised on a regular basis about developments in the law that govern life-sustaining treatment and health care more generally.
- The involvement of family members may enhance the informed consent process and assist patients and physicians to identify the best course of treatment. However, if an adult patient has decision-making capacity, or has clearly expressed a treatment decision prior to losing capacity, family members do not have the right to override the patient's wishes.
- When a physician opposes a patient's decision about life-sustaining or other treatment, the first step should be a dialogue between them. When the wishes of patients and the beliefs of physicians cannot be reconciled, the physician should transfer care of the patient to another physician willing to honor the patient's wishes.
- If another physician willing to treat the patient cannot be identified at the facility, the possibility of transferring the patient to another facility should be explored. If transfer is not possible, or is opposed by the patient or facility, the parties should seek judicial resolution. The courts are best-suited to weigh the particular circumstances and interests of the patient and facility in each case.
- Health care facilities should minimize the potential for conflict by informing patients and their families about facility policies on life-sustaining treatment prior to the patient's admission.
- All policies about life-sustaining treatment must affirm the value of life and the presumption in favor of continued treatment. However, when that presumption conflicts with the individual's decision, the individual's right to control his or her own treatment must be respected.
- While the Task Force recognizes the human significance of providing artificial nutrition and hydration, and the emotional impact its withdrawal entails for some health care professionals, it believes that these concerns do not outweigh the right of competent adults to have their wishes honored.
- The Task Force strongly believes that active measures to cause a patient's death, or "euthanasia" should not be granted legal sanction. Compassion for dying patients and their plight cannot justify a change in public policy that would allow one human being to kill another. Thus, existing laws prohibiting the taking of human life should not be modified to permit mercy killing or euthanasia.

## **Summary of Part Two: Appointing a Health Care Agent— Recommendations and Proposed Legislation**

The Task Force concluded that there is a compelling need for legislation in New York State to protect individuals' rights and interests after they have lost the capacity to participate directly in health care decisions. The Task Force recommends the enactment of legislation authorizing adults to appoint a "health care agent" by using a "health care proxy." It believes that use of a health care proxy provides the best means to protect the individual's right to have his or her wishes honored following the loss of decision-making capacity.

The Task Force has developed a legislative proposal. The policies embodied in that proposal are summarized below:

- Every competent adult should have the right to appoint a health care agent. An adult should be presumed competent unless determined otherwise by a court.
- A person should be able to appoint an agent by means of a "health care proxy," a writing signed by or at the person's direction. The person's signature should be witnessed by two adults, who should affirm that the person appointing the agent appeared to be of sound mind and free from duress.
- The Task Force proposes a standard proxy form that may, but need not, be used to appoint a health care agent. The form provides information about the potential scope of the agent's authority, especially as that authority relates to certain critical treatment decisions. The proxy form also explains how to create a proxy and how to provide special instructions for the agent.
- Persons should be permitted to delegate all or part of the authority they possess to make health care decisions, including decisions about life-sustaining treatment.

- The agent should be authorized to act only after the patient has lost the capacity to make treatment decisions. A majority of the Task Force members concluded that an agent should not be allowed to make health care decisions while the patient still has decision-making capacity because this will erode patient autonomy, create the potential for abuse and interfere with the physician- patient relationship.
- A minority of the Task Force members favor permitting an individual to create a “consultation proxy” whereby an agent may make a decision on behalf of a patient who has capacity, provided the patient approves of the agent’s involvement and the resulting decision.
- All the Task Force members believe that a proxy that becomes effective as soon as it is signed, thereby empowering the agent to make decisions without consulting or notifying the patient, is unsound and an unacceptable alternative for health care decisions.
- An informal hospital-based procedure should be used to determine that the patient lacks capacity to make treatment decisions and that the agent’s authority under a health care proxy should commence. The determination should not deprive the patient of the right to make health care decisions if the patient objects to the determination of incapacity or to the agent’s treatment decision.
- A physician should not be permitted to serve as agent and attending physician for the same patient. Hence, if a physician is appointed agent, the physician should not be allowed to serve as the attending physician when the patient loses decision-making capacity and the power under the proxy commences, unless the physician declines to act as agent.
- An operator, administrator or employee of a hospital or nursing home should not be permitted to serve as agent for a patient at the facility, unless the person is appointed prior to the patient’s admission to the facility.
- The agent should be obligated to make health care decisions in accordance with the patient’s wishes as expressed in the proxy or as otherwise known. If the patient’s wishes are not known, the agent’s decision should rest on an assessment of the patient’s best interests. The agent must obtain all relevant medical information before making decisions on a patient’s behalf.

- A person should be able to revoke a health care proxy by notifying the agent or a health care provider, orally or in writing, or by any other act that conveys the intent to revoke the proxy.
- A physician must honor an agent's decisions to the same extent as if the decisions had been made by the patient, unless the agent's authority is restricted in the patient's proxy. Nevertheless, the physician should serve as a check and balance to the agent's exercise of authority in those situations where the physician believes the agent is ill-informed, incapable of serving, or acting in bad faith.
- Agents should be protected from civil and criminal liability for decisions made in good faith on the patient's behalf. Likewise health care professionals should be protected from civil and criminal liability for honoring, in good faith, decisions by agents.
- Long-term care and mental health facilities should establish procedures to: (i) provide information to residents about their right to create a health care proxy, (ii) educate residents about health care proxies, and (iii) ensure that residents who create health care proxies while at the facility do so voluntarily and understand the benefits and risks of creating a proxy.

# **Part One**

## **The Social, Legal And Ethical Context For Treatment Decisions**



## **Introduction**

In this century, two developments have fundamentally altered the circumstances surrounding death. First, most people no longer die at home under the care of family members and friends. Instead, most dying people are treated in a health care facility, either a hospital or nursing home. Second, the growing arsenal of medical interventions available to prolong life has radically changed the number and nature of decisions that must be made.

That arsenal of treatments includes new surgical procedures such as organ transplantation and coronary bypass surgery; treatments like chemotherapy designed to eliminate or retard the disease process; and an array of life-sustaining measures such as artificial respiration to substitute for bodily functions. A precise definition of the treatments that might be considered life-sustaining in the broader sense is not possible. Several treatments, however, are most commonly associated with the term “life-sustaining treatment”: artificial respiration, dialysis, antibiotics, and artificial nutrition and hydration.

The availability of new technologies to sustain life and the related need to make decisions about when and how people die has given rise to profound legal and ethical dilemmas. While the questions posed about who decides and on what grounds arise in a medical context, the issues resonate beyond medicine to all spheres of our collective life.

The first half of this Report explores those questions as they relate to adult patients who have the ability to decide for themselves about treatment. In this context, decisions about life-sustaining treatment have forced us to reexamine the relationship between individual rights and the community’s interests. What boundaries should society establish on individual freedom in these most personal of decisions? How should those boundaries be set and how does society define its own interests in establishing them?

The social and moral implications of decisions about life-sustaining treatment have also intensified scrutiny of issues that have long been part of the clinical setting. Questions have arisen about how patient autonomy is realized in the complex relationship of patients, family members, health care professionals and institutions. The need to define the rights, duties and liabilities of all involved in the decision-making process is now more keenly felt. Moreover, legal and ethical differences in the decision-making process for patients with, and those without, capacity have been crystallized as the interests at stake in the determination escalated. Consequently, questions about the process to demarcate that critical dividing line have been raised. Who determines the patient's capacity? What standard should be used and what review or safeguards are needed to protect the patient's right to decide?

Finally, questions about life-sustaining treatment and widespread recognition of the primacy of the patient's choice in these intensely personal and value-laden decisions have spurred efforts to extend the patient's participation in these decisions beyond the patient's loss of capacity to decide. Thirty-eight states and the District of Columbia now have laws allowing patients to express their treatment preferences in writing or appoint someone to act on their behalf in the event they lose decision-making capacity. Often seen as assuring the "right to die" or the "right to death with dignity," the right at issue has a long history in our medical and legal traditions—it is the right to consent to or refuse treatment. Like other issues in the clinical setting, decisions about life-sustaining treatment have infused this right with new meanings and a sense of public urgency. The second half of this Report sets forth the Task Force's recommendations for public policy and, specifically, a legislative proposal to extend individual participation in treatment decisions beyond the loss of decision-making capacity.

## **I. Choices and Dilemmas**

Advances in medical technology have led to a proliferation of choices about medical treatment. More diseases can be cured today than ever before. However, many treatments prolong life but cannot halt the spread of progressive or degenerative illness. Other treatments provide relief only after long periods of pain and suffering. Technological advances such as the mechanical respirator can maintain the life of greatly debilitated patients, including those who have permanently lost consciousness, without hope for cure or improvement.'

Decisions about medical treatment are deeply personal. They reflect basic values, personality traits and attitudes. Often, an individual's capacity to tolerate pain, disfigurement or dependency must be considered. Health care decisions may involve weighing a fear of death against acceptance of disability. Religious and moral beliefs are also central to health care decisions, which touch upon basic understandings about human life, personal identity and obligations to self and to others.

This is especially true for decisions about life-sustaining treatment. While some individuals might choose to have their life prolonged, whatever the limitations or burdens of treatment, others would prefer an earlier death rather than endure a protracted dying process. Although pain can be reduced with available medications, the dying process for patients suffering from illnesses such as cancer may still be agonizing.

Current medical evidence suggests that when patients have permanently lost consciousness, they do not experience pain.<sup>2</sup> Nor are they necessarily terminally ill. Some permanently unconscious patients may be maintained on life-support systems, including artificial respiration and artificial nutrition, for as many as ten or even twenty years.<sup>3</sup> Nevertheless, many people would prefer an earlier death to this sustained unconscious existence, devoid of the capacities for human interaction, thought or feeling.<sup>4</sup>

Beginning in 1976 with the well-known case of Karen Ann Quinlan, issues related to life-sustaining treatment have been the focus of considerable public debate and concern. With continued public attention has come a shift in public opinion. Surveys of public attitudes about the right to refuse life-sustaining treatment have shown a steady increase in public support for the right of terminally ill patients to make decisions about their own dying process.<sup>5</sup> In a 1973

Harris Poll, 62% of the public endorsed such a right, 28% opposed it and 10% were undecided.<sup>6</sup> In 1977, 71% of the public favored granting the individual the right to refuse treatment and, by 1985, that number had climbed to an overwhelming 85%, with only 13% opposed and 2% undecided.<sup>7</sup> Moreover, since the *Quinlan* case, judicial decisions have made it increasingly clear that a person has the right to refuse treatment and to control decisions about his or her own body, even when treatment is necessary to prolong life.<sup>8</sup>

Regardless of judicial recognition of the right to decide about treatment or the overwhelming public support for protecting that right, decisions by patients are often constrained.<sup>9</sup> Some constraints are inherent in the fact that health care decisions are made in the context of a relationship with and dependence on others, including medical professionals and family members. Other constraints arise because of failures in communication between patient and physician, misunderstanding about existing law, or the need for legal reform.

### **Informing Patients**

A complete discussion of informed consent, either the principles underlying the requirement or the complicated realities of the process as it takes place in the clinical setting, is beyond the scope of this Report.<sup>10</sup> The Task Force believes that the consent process requires further exploration and a richer understanding of how the process now unfolds in the myriad of health care settings to which it is central. The Task Force wishes, however, to make a few basic recommendations about the dialogue between patient and physician in the context of decisions about life-sustaining treatment.

The requirement of informed consent evolved to protect the patient's right to decide about treatment by requiring physicians to disclose information necessary to enable patients to participate meaningfully in treatment decisions.<sup>11</sup> This legal requirement is only one part of a larger dialogue between patient and physician that forms the core of the therapeutic relationship.<sup>12</sup> Through that dialogue, the patient and physician identify their shared goals and establish a common commitment to the course of treatment. When the patient's health can be fully restored, the patient's and physician's concerns and judgment are likely to coincide. This identity of judgment and values, however, cannot be assumed for decisions about life-sustaining treatment which rest upon intensely personal preferences and beliefs. Hence, the dialogue about treatment, essential to health care decisions generally, assumes heightened significance in the context of decisions about life-

sustaining measures. Ultimately, these decisions are not medical judgments but moral choices. The dialogue between patient and physician is the necessary foundation for those choices. The Task Force strongly believes that this dialogue must be understood as a central part of the obligation of care owed to all patients.

Studies have shown that the public is keenly interested in receiving information about their medical condition and treatment.<sup>13</sup> Patients express a strong desire for information relating both to their diagnosis and prognosis as well as the risks and alternatives of treatment.<sup>1,1</sup> Based on an extensive survey, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research concluded that, "Indeed, the public displayed an unflinching desire for facts about their conditions, even dismal facts. When asked specifically whether they would want to know about a diagnosis of cancer, 96% of the public said yes."<sup>15</sup>

Studies have also revealed that the public's desire for information outstrips the disclosure provided by physicians. The divergence between patients' desire to be informed and physicians' inclination to inform them is particularly striking with respect to disclosure of alternative treatments.<sup>16</sup> Also significant is the difference between patient and physician attitudes about the impact of disclosure. For example, one study showed that physicians believe that detailed disclosure about a treatment and potential side effects or risks would reduce patient compliance with the recommended treatment. In contrast, patients reported that such disclosure would substantially increase compliance.<sup>17</sup>

The patient is profoundly dependent on health care professionals, and physicians in particular, to provide the information that is the prerequisite for treatment decisions. For decisions about life-sustaining treatment, as with other treatment decisions, physicians should provide the information essential to a genuine and knowing consent. That information should include an explanation about: (i) the patient's diagnosis; (ii) alternative treatments and the associated risks and benefits of treatment for the patient; (iii) the patient's prognosis following the course of treatment; and (iv) significant uncertainties in the evaluation of available treatments and the benefits or risks they present for the patient.<sup>18</sup> Moreover, physicians should also discuss the measures available to provide comfort and relief from pain whether the patient chooses to accept or forego aggressive treatment.

In addition to an explanation of their medical condition and treatment alternatives, patients expect and seek guidance from physicians about their decisions. This expectation is inherent in the physician's role as professional and the therapeutic bond between patient and physician. Nonetheless, this guidance must be separated from a clear explanation of the patient's medical condition and alternatives. That explanation is essential to empower patients to make an informed choice consistent with their own system of values and beliefs. While physicians may have strong convictions about the appropriate course of treatment, especially where the decision involves life-sustaining measures, those convictions must not be allowed to thwart the patient's right to receive the information essential to make a knowing and voluntary choice.

The circumstances surrounding decisions about life-sustaining treatment give rise to special obligations for health care professionals. Except in rare circumstances, decisions to forego life-sustaining treatment arise only when patients are extremely ill. While some severe illnesses leave a patient's decision-making abilities unimpaired, others diminish the person's decisional capacity. Even where there is no loss of capacity due to organic causes, the fact of illness itself creates a profound sense of vulnerability and results in a dramatic loss of control over one's body and the circumstances of one's daily existence.<sup>19</sup> The depression that often accompanies terminal or debilitating illness contributes to an overall sense of helplessness.

Patients who are dying often require the most active support and assistance of health care professionals to make informed and voluntary choices. Yet the limitations severe illness imposes on patients may cause health care professionals to withdraw from patients rather than commit the additional time and energy that communication may entail. Caring for such patients and engaging them in a dialogue about treatment choices is difficult and emotionally demanding. In addition, health care professionals committed to prolonging life may consciously or unconsciously feel that a dying patient represents a failure of their own professional skills or of the remedies medical progress can offer.<sup>20</sup> In fact, studies have shown that many professionals tend to avoid dying patients while dying patients often report feeling lonely or abandoned.<sup>21</sup>

Although it is painful to care for dying persons, the Task Force strongly believes that health care professionals should engage these patients in a dialogue about their treatment choices and foster their ability to exercise whatever degree of autonomy they still possess. Moreover, maintaining a dialogue with patients is an act of caring that recognizes and respects their dignity and moral presence.

The Task Force realizes that it is harder to care for some patients in this respect than others. Moreover, physicians' skills and commitment to communicating with patients vary enormously. In some settings, such as long-term care, the relationship between patient and physician is often attenuated and may not foster meaningful dialogue. The diminished or fluctuating capacity of some patients separates ideal and actual practice even further, perhaps isolating the patient altogether from the decision-making process except for the formality of signing a consent document. The Task Force believes that these factors must be explored as part of a broader assessment of the informed consent process and the development of policies to maximize patients' access to crucial information about their treatment.

As technologies available at the end of life continue to proliferate, patients will be increasingly reliant on health care professionals to explain those technologies—their purposes, risks, benefits and limitations. Without this explanation, the gap between physician as knowing expert and the patient as uninformed lay person will grow, leaving patients more and more helpless to participate meaningfully in decisions about their dying process. Technological advances in medicine have therefore heightened the need to enrich the dialogue between patient and physician as a primary aspect of care. Without this dialogue, patients will be denied the opportunity to answer for themselves the questions posed by the availability of life-sustaining treatment.

### **Education About Legal Rights and Responsibilities**

Health care professionals and providers are cautious in framing policies and responding to individual decisions about life-sustaining treatment. Indeed, they usually evaluate requests to forego life-sustaining treatment by competent patients or by family members on behalf of incompetent patients through a prism of concerns about civil and criminal liability.<sup>22</sup> The requests are, in fact, often handled as "risk management" problems. Yet, when decisions are made based on fear of liability, the focus of the decision shifts from a medical and ethical inquiry about the patient's interests to a strictly legal assessment of the provider's concerns.

While attention to legal considerations is an undeniable responsibility for health care administrators and a stark reality for health care professionals, the assessment of potential liability

must be squarely grounded in a responsible understanding of the law and a balanced evaluation of potential risks. An overly cautious approach will foreclose consideration of the underlying ethical issues as well as an exploration of clinical possibilities that would best serve the patient within the framework of legally acceptable alternatives.

Compliance with decisions by a competent patient presents only limited grounds for legal concerns. As stated by the President's Commission in its 1983 Report to Congress, "There is little reason to believe that liability would arise for actions taken on the basis of the decisions of competent patients that are arrived at in an appropriate fashion."<sup>23</sup> Recent judicial decisions in New York and other states provide strong support for the right to refuse treatment and corresponding protection for health care providers when they act in accordance with the informed, voluntary choices of competent adults.<sup>24</sup> Indeed, those same decisions make it clear that health care professionals may face liability for failing to honor the patient's refusal and thereby violating the patient's common law and constitutional rights.<sup>25</sup>

Concerns about liability for honoring decisions about life-sustaining treatment are especially acute in many areas of New York State. This heightened concern can be attributed, in part, to the apparent willingness of local prosecutors to aggressively pursue cases involving the withdrawal of life-sustaining treatment.<sup>26</sup>

The Task Force respects the responsibilities and independence of local prosecutors in New York State. However, in cases concerning life-sustaining treatment, it urges them to recognize the impact their statements may have on the ability of patients to exercise fundamental rights about health care.

While the chilling effect of any such statements is inevitable, health care providers must assess such statements carefully in the context of statutes and judicial decisions clarifying and protecting the patient's right of informed consent. Concerns about liability must also be balanced against respect for the patient's basic right to decide about treatment. Finally, the actual risk of prosecution must be realistically assessed. To date, no physician in New York State has been prosecuted for withdrawing or withholding life-sustaining treatment from a patient. Only one such case has ever been brought nationally. That case involved an incompetent patient and was dismissed before it even reached trial.<sup>27</sup>

The Task Force believes that a broad educational effort is essential to clarify misconceptions about the rights of patients to



make health care decisions and the legal obligations and protections afforded health care professionals. While certain aspects of the law on these issues remain unclear or undeveloped in New York State, several important legal principles have been established in judicial decisions.<sup>28</sup> Nonetheless, the force of these principles is undermined because health care professionals and patients often misunderstand or lack knowledge of them. For example, a Task Force survey of all nursing homes and hospitals in the State revealed that many health care facilities have concluded that living wills cannot be recognized legally and refuse to honor the documents.<sup>29</sup> Yet, a 1981 Court of Appeals decision, *Eichner v. Dillon*, provides strong support for reliance upon any document that offers clear evidence of the patient's wishes.<sup>30</sup>

It also appears that many health care professionals believe that there is a clear legal distinction between the withdrawal and withholding of life-sustaining treatment such as artificial respiration. There is, in fact, no support for the distinction under New York law.<sup>31</sup> Nonetheless, this misconception about legal norms may distort the decision-making process and inhibit the provision of treatment that might be highly beneficial to the patient. If physicians believe that treatment, once begun, cannot be withdrawn, they may be less willing to recommend that treatment be initiated.

Hence, the Task Force urges that widespread education and discussion regarding decisions about life-sustaining treatment should be undertaken. The ethical issues underlying the decisions should be explored and misunderstandings about legal consequences and parameters must be clarified. This educational process should be far-reaching and designed to stimulate public discussion of the values and concerns at issue. Associations representing health care facilities and professionals as well as patient advocacy groups should promote this educational effort.

The Task Force also believes that counsel for hospitals, long-term care and mental health facilities have a special responsibility to educate health care professionals about the law pertaining to patients' rights and the obligations of health care professionals in the consent and treatment process. In the absence of such efforts, health care professionals may be unaware of or misinformed about existing law and important legal developments. The Task Force therefore urges lawyers and administrators for health care facilities to create a process by which medical professionals can be educated and advised on a regular basis about the law that governs life-sustaining treatment and health care more generally.

### **Autonomy in the Company of Others**

Patients have a legal and moral claim to autonomy in their decisions about treatment. That autonomy, however, is exercised in the context of interdependence with others. The patient's decisions must be carried out by health care professionals who often have their own strong personal or professional convictions about the appropriate course of treatment. Family members also play an important role in the decision-making process.

#### **The Family**

The involvement of family members may enhance the informed consent process and assist patients and physicians to identify the best course of treatment. Moreover, when family members are informed about the nature and purpose of the treatments provided, they can deepen the patient's understanding and improve the patient's compliance with recommended therapies.

The family's role, however, is a limited one. In the informed consent process, those limits are defined by the privilege of confidentiality between patient and physician. Where health care decisions are concerned, the family's role is firmly bounded by the patient's right to decide about his or her own treatment. If the patient is an adult and has decision-making capacity, or has expressed a treatment decision prior to losing capacity, family members do not have the right to override the patient's wishes.

In many cases, family members unwilling or unable to accept the patient's impending death need counseling and support. Pastoral or therapeutic assistance should be offered to help family members confront their own feelings and respect the patient's decisions.

#### **Health Care Professionals**

Health care professionals often have strong feelings about patients' choices concerning life-sustaining treatment. They are dedicated to the preservation of life and the relief of suffering, two goals that may come into conflict in decisions about life-sustaining treatment. When this happens, professionals' responses are shaped by their own moral and religious views, their medical training, the policies of the health care facility, and a conception of their obligations to patients.

When a physician opposes a patient's decision about treatment, the first step should be a dialogue between them. The patient's decision may be based on inadequate information while the physician may not have fully considered the patient's point of view. Studies have shown, in fact, that patients' refusal of treatment often reflect a failure in the decision-making and consent process.<sup>12</sup> One study concluded that many patients appeared to refuse treatment as a way of obtaining more information about their care.<sup>33</sup> Equally striking, the study noted that physicians' response to the refusal rarely related to the patients' reasons for refusing because little or no effort was made to ascertain those reasons by talking to the patient.<sup>34</sup> Although it is unlikely that patients will decline life-sustaining measures to obtain more information, the refusal should lead to a dialogue about the reasons for the refusal and should enhance the patient's understanding of treatment alternatives and available care for discomfort and pain.

In some cases, the wishes of patients and the beliefs of health care professionals cannot be reconciled. The physician should then assume responsibility to assist transfer of the patient to another physician. If no physician with the necessary expertise to treat the patient can be identified at the facility, the possibility of transferring the patient to another facility should be pursued.

It may not always be possible to transfer the patient. The patient's medical condition may foreclose this option or there may not be another facility willing to admit the patient. In New York, as elsewhere, this latter problem is most likely to arise in connection with the withdrawal of artificial nutrition and hydration. At present, even facilities that do not have ethical objections to the withdrawal of artificial nutrition and hydration are reluctant to accept patients who wish to forego these measures because the law on this issue is still evolving.

Several courts have recently addressed the question of a facility's obligation to treat a patient when the facility objects on professional or ethical grounds to the course of treatment chosen by the patient. In a recent New York case, *Matter of Delio*, an appellate court upheld the patient's right to forego artificial nutrition and hydration, but allowed the facility to transfer the patient rather than contravene its view of its ethical and moral duty.<sup>35</sup> The Supreme Judicial Court of Massachusetts took a similar approach in *Brophy v New England Sinai Hospital*.<sup>36</sup> In contrast, courts in California, New Jersey and Colorado have ruled that facilities could not involuntarily transfer patients who refused treatment." Those courts found it significant that the facilities had not informed patients about their policies on life-

sustaining treatment prior to the patients' admission, and that the proposed transfer would be impractical or burdensome to the patient.

The Task Force believes that the need to transfer patients will arise less frequently as judicial decisions clarify the legal issues concerning the right to refuse artificial nutrition and hydration. Nonetheless, where a conflict arises and transfer is not possible, or when it is opposed by the patient or the patient's family, the parties should seek judicial resolution. The judicial process is the appropriate forum to explore the particular circumstances of each case: the interests of the patient and facility, an assessment of the harm transfer would impose on the patient, and the alternatives available to each of the parties.

The Task Force recommends that health care facilities should minimize the potential for conflict by informing patients and their families about facility policies concerning life-sustaining treatment. This information should be provided prior to the patient's admission, when the patient or family members acting on a patient's behalf are able to make other arrangements.

### **The Loss of Decision-Making Capacity**

Often at the crucial time when health care decisions must be made, the patient is incapable of participating in the decision-making process. This loss of capacity is the single greatest barrier to ensuring that a person's wishes about treatment are honored.

Without some procedure to allow individuals to express their wishes and thereby extend their autonomy beyond the loss of decision-making capacity, individuals are rendered powerless to control the course of their medical treatment. Following the loss of capacity, a person's intensely held feelings about treatment may be overwhelmed by the emotional needs of family members, the professional ethos of health care providers, or the policies of medical facilities. In some cases, treatment may be discontinued or withheld in contravention of the patient's preferences. In other instances, the patient's wishes cannot be honored simply because there is no process for consent to withhold or discontinue life-sustaining treatment for patients who have lost decision-making capacity and did not leave clear evidence of their wishes. As a result, patients who do not express their wishes about treatment in advance lose the right to forego

treatment when they lose the capacity to make treatment decisions. The technologies available to sustain life then shift from options to imperatives.

### **Withdrawing and Withholding Life-Sustaining Treatment**

When patients lose decision-making capacity and have not provided advance instructions or guidance, decisions about the withdrawal and withholding of life-sustaining measures are especially complex and difficult for family members. Family members who speak with one voice about the provision of highly effective treatment may disagree profoundly about the decision to forego life-sustaining measures. Their judgment may be clouded by denial or guilt as they confront not only their grief, but the responsibility for making unprecedented and irrevocable decisions. Moreover, under current New York law, even where family members are certain that the cessation of treatment would be consistent with the patient's wishes and the best possible outcome under the circumstances, they have no legal authority to speak for the patient and are helpless to end a course of treatment that they believe violates the patient's values and dignity.<sup>38</sup>

The same is true for health care providers. Where the patient has failed to leave instructions about life-sustaining treatment, health care professionals may be forced to choose between providing treatment indefinitely and risking civil or criminal liability for discontinuing it.<sup>39</sup> An assessment of what is medically and ethically appropriate is then subordinated to strictly legal considerations about authorization to discontinue treatment. Concerns about cost may also affect the decision-making process and may lead to the provision of less aggressive treatment than the patient would have chosen under the circumstances.

Currently, even when patients provide advance written instructions about treatment in the form of a living will or other document, their wishes are often not honored despite legal support for reliance on those instructions.<sup>40</sup> If the patient has appointed someone else to act on his or her behalf, the legal status of the appointment is uncertain under New York law; the majority of hospitals and nursing homes will not honor the appointment for decisions about life-sustaining treatment.<sup>41</sup>

### **Providing Treatment**

When a patient loses the capacity to make health care decisions, it may also create a significant hurdle to the provision of needed treatment. Except for emergencies, when consent is not required, treatment cannot be provided without it.<sup>42</sup> When a patient lacks decision-making capacity, someone else must consent on the patient's behalf. That person must have an appropriate relationship to the patient as well as legal authority to grant consent.

Under current New York law, even family members do not have clear legal authority to consent to treatment.<sup>43</sup> Based on long-standing social and medical traditions, health care professionals accept consent from family members.<sup>44</sup> However, persons other than family members, no matter how close their relationship to the patient, are rarely allowed to provide consent.

When family members are not available or are not willing to act on a patient's behalf, hospitals are generally forced to seek court approval for treatment, even for routine surgical procedures that are clearly beneficial for the patient.<sup>45</sup> This can be a costly, cumbersome process that leaves patients needing treatment dependent on the judicial process for medical care. Judicial involvement in these medical decisions is especially burdensome for the courts because of the many persons who need medical treatment and have no family members to act on their behalf.

### **The Need for Legislation**

The Task Force concluded that there is a compelling need for legislation in New York State to ensure that individuals' wishes about treatment will be followed even after they have lost the capacity to participate in the decision-making process. The legislation must establish clear rules for consent for the provision or withholding of treatment in accordance with the previously expressed wishes and values of adults who are no longer capable of deciding for themselves. That consent process should protect the right to forego life-sustaining measures as well as the right to consent to those measures and other treatment.

The Task Force has devised a legislative proposal that seeks to achieve these goals. That proposal is set forth in Appendix A. Part Two of this Report describes the framework and policies for that legislation.

## Footnotes

1. Patients who are permanently unconscious have lost all thought, sensation, and awareness. This includes patients in a persistent vegetative state, patients who are totally unresponsive following brain injury or hypoxia, and patients at the end stage of certain degenerative neurological conditions. See President's Commission for the Study of Ethical Issues in Medicine and Biomedical and Behavioral Research, ***Deciding to Forego Life-Sustaining Treatment*** (Washington, D.C.: U.S. Gov't. Printing Office, 1983), p. 177.
2. See Ronald Cranford, "Patients with Permanent Loss of Consciousness," in ***By No Extraordinary Means***, Joanne Lynn (ed.) (Bloomington: University of Indiana Press, 1986), p. 186; Brief of Amicus Curiae American Academy of Neurology at 10-29, ***Brophy v. New England Sinai Hospital***, 398 Mass. 417, 497 N.E.2d 626 (1986); President's Commission, ***Deciding to Forego Life-Sustaining Treatment***, p. 177.
3. In one recorded case, the patient survived in a permanently unconscious state for 37 years; in another, for 18 years. President's Commission, ***Deciding to Forego Life-Sustaining Treatment***, pp. 181-82.
4. This is perhaps best illustrated by the growing number of persons who create living wills and other advance directives. Society for the Right to Die, an organization that promotes the use of living wills, has estimated that approximately 80,000 people in New York State have executed living wills. See ***Saunders v. State of New York***, 129 Misc. 2d 45, 492 N.Y.S.2d 510, 513 (Sup. Ct., Nassau Co. 1985).
5. Harris Survey, March 4, 1985.
6. *Id.*
7. *Id.*
8. See discussion, Chapter II. See also, Concern for Dying, ***The Living Will and Other Advance Directives: A Legal Guide to Medical Treatment Decisions*** (New York: 1986).
9. See President's Commission, ***Deciding to Forego Life-Sustaining Treatment***, pp. 91-118.
10. For a detailed exploration of informed consent, see Tom Beauchamp and Ruth Faden, ***A History and Theory of Informed Consent*** (New York: Oxford University Press, 1986); Jay Katz, ***The Silent World of Doctor and Patient*** (New York: The Free Press, 1984);

President's Commission for the Study of Ethical Issues in Medicine and Biomedical and Behavioral Research, *Making Health Care Decisions*, Vol. 1, 2 (Washington, D.C.: U.S. Gov't. Printing Office, 1982).

11. In New York, physicians have a statutory obligation to disclose the foreseeable risks and benefits of a proposed treatment and its alternatives that a reasonable practitioner would have disclosed. New York Public Health Law § 2805-d.1. This standard of disclosure is less stringent than the standard in many other states that requires the physician to disclose what a reasonable patient would want to know. The New York informed consent statute recognizes several exceptions to the physician's duty to obtain informed consent, such as when emergency treatment is required, when the patient knowingly waives the right to be informed, and when full disclosure could "adversely and substantially affect the patient's condition." *Id.* § 2805-d.2, 4. See generally, James Morrissey, "Informed Consent: The New York Approach," *N.Y.S.J.Med.*, Vol. 85, May 1985, p. 210; Alan Meisel and Lisa Kabnick, "Informed Consent to Medical Treatment: An Analysis of Recent Legislation," 41 *U.Pitt. L. Rev.* 407 (1980); Alan Meisel, "The 'Exceptions' to the Informed Consent Doctrine: Striking a Balance between Competing Values in Medical Decision Making," 1979 *Wise. L. Rev.* 413; Jeffrey Schreiber, "Dries vs. Gregor: A Case Study of Informed Consent Doctrine in New York," *N.Y.S.Bar J.* October 1981, p. 431; Alan J. Weisbard, "Informed Consent: The Law's Uneasy Compromise with Ethical Theory," 65 *Neb. L. Rev.* 749 (1986).

12. Paul Ramsey explains the role of consent in the partnership between patient and physician as follows:

No man is good enough to cure another without his consent. This holds without exception for ordinary medical practice. This is the negative contract between physician and patient, even if it serves mainly to direct us to the positive role, to the need for a patient's partnership in his own cure.

*The Patient as Person* (New Haven: Yale University Press, 1970), p. 7.

13. E.g., Ruth Faden, Catherine Becker, Carol Lewis, John Freeman and Alan Faden, "Disclosure of Information to Patients in Medical Care," *Medical Care*, Vol. 19, July 1981, pp. 718, 730; Robert Veatch, *Death, Dying and the Biological Revolution* (New Haven: Yale University Press, 1976), pp. 229-31; John Robertson, *The Rights of the Critically III* (New York: Bantam, 1983), p. 9.



14. For example, in a poll of 1,251 persons conducted for the President's Commission, 94% of those polled stated that they would want their doctor to tell them everything about their medical condition, even if it were unfavorable. Only 4% said they would not want the information and 1% were unsure. President's Commission, *Making Health Care Decisions*, Vol. 2, p. 136.
15. President's Commission, *Making Health Care Decisions*, Vol. 1, p. 75. See generally, Katz, pp. 165-206; Raymond Duff and A.G.M. Campbell, "Moral and Ethical Dilemmas in the Special Care Nursery," *NEJM*, Vol. 289, No. 17, Oct. 25, 1973, p. 892; Stephen Newman, "Treatment Refusals for the Critically and Terminally 111: Proposed Rules for the Family, the Physician and the State," 3 *N.Y. Law Sch. Human Rights Ann.* 35, 61-63 (1985).
16. President's Commission, *Making Health Care Decisions*, Vol. 1, p. 80.
17. Faden et al., p. 728. For a further challenge to the view that full disclosure negatively affects patient decision-making, see Elizabeth Patterson, "The Therapeutic Justification for Withholding Medical Information: What You Don't Know Can't Hurt You, Or Can It?," 64 *Neb. L. Rev.* 721, 752 (1985).
18. For a discussion of physician and patient attitudes about uncertainty and the hesitancy of physicians to disclose uncertainties, see President's Commission, *Making Health Care Decisions*, Vol. 1, pp. 85-93; Katz, pp. 165-206.
19. Edmund Pellegrino and David Thomasma describe this vulnerability as a special and critical dimension of the patient-physician relationship. See *A Philosophical Basis of Medical Practice* (New York: Oxford University Press, 1981), p. 208.
20. See generally, Katz, p. 219; Newman, p. 61.
21. Katz, pp. 207-29; President's Commission, *Deciding to Forego Life-Sustaining Treatment*, p. 58.
22. Alexander Capron wryly states, "If patients behaved as irrationally about treatment as physicians do about liability, the patients would be labeled incompetent." "Legal and Ethical Problems in Decisions for Death," *Law, Med. & Health Care*, Vol. 14, No. 3-4, Sept. 1986, p. 142.

23. President's Commission, *Deciding to Forego Life-Sustaining Treatment*, p. 93. See also, Gregory R. Ginex, "A Prosecutor's View of Withholding or Withdrawing Medical Care: The Myth and the Reality," in *Legal and Ethical Aspects of Treating Critically and Terminally Ill Patients*, A. Edward Doudera and J. Douglas Peters (eds.) (Ann Arbor: AUPHA, 1982), pp. 205-10.
24. See *Eichner v. Dillon*, 52 N.Y.2d 363, 438 N.Y.S.2d 266, 420 N.E.2d 64, *cert. denied*, 454 U.S. 858 (1981). See generally, Chapter 11.
25. Where decisions about life-sustaining treatments are involved, facilities tend to evaluate only one side of the equation of risks and benefits—the potential criminal or civil liability for honoring the patient's wish to forego treatment. Yet any treatment decision involves two basic rights—the right to consent to treatment and the right to refuse. It has long been recognized in this State that a physician who treats a patient without consent does so at his or her own risk and may face civil liability. Lawsuits claiming battery or violation of a patient's constitutional and civil rights due to the provision of life-sustaining treatment without consent are not common. However, several such cases have been brought in recent years and the number may increase following recent court decisions that strongly affirm the patient's right to forego treatment. See, e.g., *Bartling v. Glendale Adventist Medical Center*, 229 Cal. Rptr. 360 (Ct. App. 1986); *Leach v. Shapiro*, 13 Ohio App. 3d 393, 469, N.E.2d 1047 (Ct. App. 1984). See also, "Damage Actions for Nonconsensual Life-Sustaining Medical Treatment," 30 *St. Louis ULJ* 895 (1986); A. Samuel Oddi; "The Tort of Interference with the Right to Die: The Wrongful Living Cause of Action," 75 *Georgetown L. Rev.* 625 (1986).
26. For example, one district attorney warned that his office would prosecute cases concerning the withholding of treatment if a complaint was filed. "Negotiated Death: An Open Secret," *New York Times*, Dec. 18, 1984, p. 36. A 1982 Grand Jury investigation found that decisions about cardiopulmonary resuscitation are more frequently made on the basis of legal considerations in New York than in other states. This was attributed to the prevalence of litigation in this state as well as to the broad discretion vested in local prosecutors. See *Report of the Special January Third Additional 1983 Grand Jury Concerning "Do Not Resuscitate" Procedures at a Certain Hospital in Queens County* p. 18. (Sup. Ct., Queens Co., Feb. 8, 1984).
27. In *Barber v. Superior Court*, 147 Cal. App. 3d 1006, 195 Cal. Rptr. 484 (Ct. App. 1983), charges were brought against two doctors who, at the request of the patient's family, disconnected a respirator and withdrew feeding tubes from a terminally ill man in a

vegetative state. The charges were dismissed by an appellate court prior to trial. The court found that the discontinuance of treatment was not unlawful because the patient had virtually no chance of regaining consciousness. Moreover, the court held that the patient's family members were the appropriate persons to make the decision on his behalf, and that there was no requirement to obtain court approval.

28. See discussion, Chapter II.
29. See Appendix B, Tables E-G, pp. 174-77.
30. See *Eichner u. Dillon*, 52 N.Y.2d 363, 379.
31. New York courts apply the same legal analysis in cases involving the withholding of treatment as in cases involving withdrawal. Compare, e.g., *Randolph v. City of New York*, 117 A.D. 2d 44, 501 N.Y.2d 827 (1st Dept. 1986) (physicians lawfully withheld blood transfusion based on patient's instructions) with *Eichner v. Dillon*, 52 N.Y.2d 363 (physicians could lawfully withdraw respirator based on clear and convincing evidence of patient's wishes). As the trial court judge stated in the *Eichner* case, "It is important that the law not create a disincentive to the fullest treatment of patients by making it impossible for them in at least some extreme circumstances to choose to end treatment which has proven unsuccessful." *Eichner u. Dillon*, 102 Misc. 2d 184, 423 N.Y.S.2d 580, 594 (Sup. Ct., Nassau Co. 1979).
32. President's Commission, *Making Health Care Decisions*, Vol. 2, p. 317.
33. Paul Appelbaum and Loren Roth, "Patients Who Refuse Treatment in Medical Hospitals," *JAMA*, Vol. 250, No. 10, Sept. 9, 1983, pp. 1296, 1299.
34. *Id.*
35. *Matter of Delio*, N.Y.L.J., June 4, 1987. p. 1, col. 6, p. 35, col. 1 (App. Div., 2d Dept.).
36. *Brophy v. New England Sinai Hospital*, 398 Mass. 417, 497 N.E.2d 626(1986).
37. *Bouvia u. Superior Court*, 179 Cal. App. 3d 1127 (1986); *In re Requena*, 517 A.2d 859 (1986); *Matter of Rodas*, No. 86PR139 (Dist. Ct., Mesa Co. Colo., Jan. 22, 1987). See also, George Annas, "Transferring the Ethical Hot Potato," *Hastings Ctr. Rpt.*, Vol. 17, No. 1, Feb. 1987, p. 20, endorsing this approach.

38. See *Matter of Storar*, 52 N.Y.2d 363, 438 N.Y.S.2d 266, 420 N.E.2d 64, *cert. denied*, 454 U.S. 858 (1981).
39. *Id.*
40. See Appendix B, Tables E-G, pp. 174-77.
41. See pp. 79-80. See also, Appendix B, Table H, pp. 178-79.
42. New York Public Health Law § 2805-d (McKinney's Supp. 1987). See generally, Michael MacDonald, Kathryn Meyer and Beth Essig, *Health Care Law: A Practical Guide* § 18.02 (New York: Matthew Bender 1985); *Hospital Law Manual* (Aspen 1985) §§ 8, 9.
43. On the legal uncertainty about decisions by family members regarding health care in New York and other states, see "Proxy Consent for Incompetent Non-Terminally 111 Adult Patients," 6 *J. Legal Med.* 19-21 (1985); "Note, Appointing an Agent to Make Medical Treatment Choices," 84 *Col. L. Rev.* 985, 994 (1984). See also, Comment, "The Role of the Family In Medical Decisionmaking for Incompetent Adult Patients: A Historical Perspective and Case Analysis," 48 *U. Pitt. L. Rev.* 539 (1987); MacDonald et. al., p. 18-53.
44. "Appointing an Agent," p. 994; MacDonald et al., p. 18-53.
45. See MacDonald et al., p. 18-55. Conversations with legal counsel for several New York hospitals, including Kathleen Burke (New York Hospital-Cornell Medical Center); Michael MacDonald (Mt. Sinai Medical Center); Kathryn Meyer (Beth Israel Medical Center); Annette Johnson, (New York University Hospital); Salvatore Russo (New York City Health & Hospitals Corporation), July 1986.

## II. The Right to Make Health Care Decisions: New York State Law

### Adults With Decision-Making Capacity

It has long been recognized that competent adults have the right to make decisions about their own health care. As Judge Cardozo stated in *Schloendorff v. Society of New York Hospital*, a 1914 New York Court of Appeals decision:

Every human being of adult years and sound mind has the right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent commits an assault, for which he is liable in damages.<sup>1</sup>

Recent court rulings establish that an adult's control over health care decisions extends to decisions about life-sustaining treatment. In *Eichner v. Dillon*, a 1981 case, the New York Court of Appeals held that the common law and statutes of New York consistently support the right of a competent patient to refuse medical treatment, even where the treatment is beneficial or necessary to save the patient's life.<sup>2</sup> The Court also ruled that the refusal of life-sustaining treatment is not suicide unless the underlying illness or condition is self-inflicted. Further, the Court concluded that the patient's right to forego treatment overrides the physician's obligation to treat the patient and affirmed that physicians who provide treatment without consent may face civil liability. More recently, in *Rivers v. Katz*, a 1986 decision involving the refusal of antipsychotic medication by residents in a mental health facility, the Court of Appeals extended the protection accorded the right to refuse treatment by holding that the right is guaranteed by the Due Process Clause of the New York State Constitution.<sup>3</sup>

Early decisions in other states, notably the landmark 1976 New Jersey decision, *Matter of Quinlan*, held that the patient's right to refuse treatment depended, in part, on two criteria: the invasiveness of the proposed treatment and the patient's prognosis.<sup>4</sup> Under the formula laid out by the Court, as the invasiveness of treatment increased and the prognosis worsened, the patient's right to refuse was strengthened.

Recent appellate decisions in several states, including New Jersey, have abandoned or retreated from that analysis.<sup>5</sup> As stated by the New Jersey Supreme Court in a 1985 decision, *Matter of Conroy*,

Of course, a patient's decision to accept or reject medical treatment may be influenced by his medical condition, treatment, and prognosis; nevertheless, a competent person's common-law and constitutional rights do not depend on the quality or value of his life.<sup>6</sup>

With the exception of some lower court decisions involving the refusal of artificial nutrition and hydration, New York court decisions have not conditioned the right to refuse treatment on the patient's prognosis or the nature of the treatment.<sup>7</sup> Indeed, in numerous cases, the courts have upheld the right of competent adults to forego medical procedures for treatable life-threatening conditions.<sup>8</sup>

The limitations on the right to refuse treatment recognized by New York State courts relate to situations where the refusal would create a danger to public health or would substantially impair the interests of others.<sup>9</sup> For example, treatment decisions have been overridden in cases where the patient who declines life-saving treatment is a parent responsible for the care of a young child.<sup>10</sup>

Recently, controversy has centered upon whether the right to refuse treatment includes the right to forego the provision of nutrition and hydration by artificial means, i.e., by feeding tubes inserted in the patient's veins, nose and throat, stomach or intestine. In *Matter of Delio*, the only New York appellate decision that addresses the issue, the court upheld the patient's right to refuse artificial nutrition and hydration.<sup>11</sup> Daniel Delio, a 33 year-old man, was left permanently unconscious following surgery. His wife sought authority to withdraw the feeding tubes that were sustaining his life. The trial court found clear evidence that Daniel Delio, if competent, would refuse such treatment. Nevertheless, the court concluded that it lacked the authority to permit a young, non-terminally ill patient to forego nutrition and hydration and denied his wife's petition.<sup>12</sup>

The appellate court reversed and held that the withdrawal or withholding of artificial nutrition and hydration should be evaluated in the same manner as decisions to forego other life-sustaining treatments.<sup>13</sup> It emphasized that "the primary focus...is upon the patient's desires and his right to direct the course of his medical treatment rather than upon the specific treatment involved."<sup>14</sup> The court also ruled that Delio's refusal of treatment did not constitute suicide, since he did not wish to

die, but only to live free from unwanted mechanical devices and to allow nature to take its course.<sup>15</sup>

The *Delio* decision supersedes a series of prior lower court decisions in New York that had declined to authorize the discontinuance of artificial nutrition and hydration, despite clear evidence that the patients would have wanted the treatment withdrawn.<sup>16</sup> Those courts, like the lower court in *Delio*, relied primarily on a distinction between the provision of artificial nutrition and hydration and other treatments.

The *Delio* holding makes New York caselaw consistent with judicial decisions in six other states where appellate courts have addressed this issue.<sup>17</sup> In each of those cases, the court held that the provision of artificial nutrition and hydration is medical treatment and may be withheld or withdrawn in accordance with the patient's wishes. Underlying these decisions is a recognition that it is not the nature of the treatment, but the right of a competent adult to control decisions about his or her own treatment that is determinative.<sup>18</sup>

### **Determining Capacity**

The determination of a patient's capacity to make treatment decisions is a critical dividing line. Patients with decision-making capacity have a constitutional and common law right to control the course of their medical treatment.<sup>19</sup> When patients are determined to lack capacity, they lose this right. Unless a patient provided advance instructions, treatment decisions will be made by others.<sup>20</sup>

Currently, the only generally available and legally recognized process to determine capacity is a judicial determination.<sup>21</sup> In judicial proceedings to determine capacity, the patient is presumed to have capacity until established otherwise by clear and convincing evidence.<sup>22</sup> Generally, the expert opinion of psychiatrists and other physicians is the most significant evidence before the court.<sup>23</sup> The patient's refusal of life-sustaining treatment cannot, by itself, support a finding of incapacity. Independent proof of the patient's inability to make treatment decisions in a knowing and voluntary manner must be presented.<sup>24</sup>

Although only judicial decisions about capacity have clear legal recognition, the capacity of patients to make health care decisions is rarely determined in a court room.<sup>25</sup> The clinical demands of medical practice require that physicians and other health care professionals routinely evaluate the capacity of the patients they treat. These assessments are made informally at the

patient's bedside in accordance with the policies of the facility or, where there is no policy, in accordance with the individual practices of the patient's physicians.

### **Decision-Making for Adults Who Lack Capacity**

When a patient lacks capacity to make decisions about life-sustaining treatment, the crucial legal issues are whether a substitute decision may be made by a family member or other person on the patient's behalf, and how to protect the patient's dual rights: the right to refuse treatment and the right not to have life foreshortened. Courts in many states other than New York have upheld the validity of substitute decision-making for life-sustaining treatment, subject to a variety of safeguards.<sup>26</sup>

In contrast, the New York Court of Appeals in two companion cases, *Eichner v. Dillon* and *Matter of Storar*, declined to recognize the legality of decisions to forego life-sustaining treatment made by family members or others on a patient's behalf.<sup>27</sup> *Eichner v. Dillon* concerned Brother Fox, an elderly member of a religious order, who had been declared permanently unconscious. A friend and colleague, Father Eichner, sought a court order permitting the removal of a mechanical respirator that maintained Brother Fox's breathing and circulation. The Court held that when a patient is incompetent, life-sustaining treatment can be withdrawn only if there is "clear and convincing evidence" that the patient, if competent, would want the treatment stopped. It found that oral statements made by Brother Fox several years earlier satisfied this clear and convincing evidence standard and authorized removal of the respirator.

*Matter of Storar* involved a 52 year-old profoundly retarded man, John Storar. At the time the case was brought, he was dying from bladder cancer and had only two to six months to live, even with aggressive treatment. His mother, previously appointed his legal guardian, opposed the continued provision of blood transfusions that would prolong his life but could not cure the underlying disease.

The Court explained that it was unrealistic to attempt to determine what John Storar would have chosen for himself, since he never had capacity to make treatment decisions. It refused to grant Mrs. Storar's request, holding that no one, not even a family member, could consent to the withdrawal of life-



sustaining treatment on behalf of another person. Four years after the *Storar* decision, the Court restated its opposition to surrogate decision-making in *People v. Eulo*, a case involving the legal standard to determine death.<sup>28</sup>

Thus, current New York law recognizes that life-sustaining treatment may be withdrawn from a patient who lacks capacity only if there is clear and convincing evidence of the patient's wish to refuse the treatment. Absent clear evidence of that wish, even caring family members cannot make the decision on the patient's behalf. For persons never capable of expressing their wishes, life-sustaining treatment cannot be discontinued, whatever burden it imposes.

Several court decisions have considered whether the evidence of a patient's wishes to decline life-sustaining treatment satisfied the clear and convincing standard. In *Matter of Delio*<sup>29</sup>, *Matter of Triarsi*<sup>30</sup>, *In re Moschella*<sup>31</sup> and *Application of Lydia E. Hall Hospita*<sup>32</sup>, cases involving permanently unconscious patients, the courts authorized the withdrawal of treatment based on testimony by family members about the patient's prior oral statements.

Two lower court decisions have evaluated the use of a living will as evidence of the patient's wishes. A 1985 supreme court decision, *Matter of Saunders*, held that a living will constituted consent to the withdrawal of treatment and should be honored by physicians in the event the patient subsequently loses capacity.<sup>33</sup> However, in *Matter of Essner*, a Bronx supreme court disregarded an incompetent patient's living will and permitted the amputation of the patient's gangrenous leg.<sup>34</sup> The living will, created by Essner seven years earlier, stated simply that she did not want "any lifesaving or otherwise unnecessary operations to be performed on me...I want to die in dignity." After noting that death from gangrene would not be "death with dignity," the court ruled that the living will did not constitute clear evidence of Essner's wishes.<sup>35</sup>

## Footnotes

1. 211 N.Y. 125, 129-30, 105 N.E. 92 (1914).
2. 52 N.Y.2d 363, 377, 438 NYS.2d 266, 273, 420 N.E.2d 63, *cert. denied*, 454 U.S. 858 (1981).
3. 67 N.Y.2d 485, 493, 504 NY.S.2d 74, 78, 495 N.E.2d 337 (1986). Courts in several states have held that the right to refuse treatment falls within the right to privacy protected by the United States Constitution. E.g., *In re Quinlan*, 70 N.J. 10, 355 A.2d 647, 663. *cert. denied sub nom. Garaer u. New Jersey*, 428 U.S. 922 (1976); *Superintendent of Belchertown State School v. Saikewicz*, 373 Mass. 728, 370 N.E.2d 417, 424 (1977); *Satz v. Perlmutter*, 379 So.2d 359, 360 (Fla. 1980); *Matter of Welfare of Colver*, 99 Wash. 2d 114, 660 P.2d 738, 741 (1983); *Matter of Conservatorship of Torres*, 357 N.W.2d 332, 339 (Minn. 1984); *In re L.H.R.*, 253 Ga. 439, 321 S.E.2d 716, 722 (1984); *Bartling v. Superior Court*, 163 Cal. App. 3d 186, 209 Cal.Rptr. 220, 225 (Ct. App. 1984). Since neither the United States Supreme Court nor the New York Court of Appeals has ruled on this matter, the question remains unsettled in New York. The significance of the question, however, is largely undermined by the Court of Appeals decision in *Rivers v. Katz*, recognizing a State Constitutional right to decline treatment. As a result of *Rivers*, the right to refuse treatment will remain constitutionally protected in this State, regardless of whether a parallel right under the Federal Constitution is recognized.
4. E.g., *In re Quinlan*, *supra*, 355 A.2d at 664. See also. *Matter of Welfare of Colyer*, *supra*, 660 P.2d at 743; *Matter of Spring*, 380 Mass. 629, 405 N.E.2d 115, 119 (1980).
5. E.g., *Brophy v. New England Sinai Hospital, Inc.*, 398 Mass. 417, 497 N.E.2d 626 (1986); *Matter of Conroy*, 98 N.J. 321, 486 A.2d 1209 (1985); *Bouvia v. Superior Court of the State of California for the County of Los Angeles*, 179 Cal. App. 3d 1127, 225 Cal.Rptr. 297 (Ct. App. 1986).
6. *Matter of Conroy*, *supra*, 486 A.2d at 1233. The patient in this case, Claire Conroy, was terminally ill and incompetent. Nevertheless, the New Jersey Supreme Court, like other courts that have addressed similar cases, discussed the legal principles governing the refusal of treatment by competent patients.

7. Although *Eichner* involved a terminally ill patient, the Court did not identify the patient's prognosis as one of the factors it recognized as potential limitations on the right of a competent adult to refuse treatment. *Eichner v. Dillon*, *supra*, 52 N.Y.2d at 376-77. See also, *Matter of Delio*, N.Y.L.J., June 4, 1987, p. 1, col. 6, p. 35, col. 1 (App. Div., 2nd Dept.).

8. See *Randolph v. City of New York*, 117 A.D.2d 44, 501 N.Y.2d 827 (1st Dept. 1986) (acknowledging patient's right to decline life-saving blood transfusion); *Danes v. Ambrose*, 80 A.D.2d 963, 437 N.Y.2d 784 (3d Dept. 1981) (upholding patient's refusal of consent to surgical removal of infected metal pin); *Matter of Roosevelt Hospital*, N.Y.L.J. Jan. 13, 1977, p. 7 (Sup. Ct., New York Co.) (upholding decision to forego amputation of gangrenous leg); *Matter of Melideo*, 88 Misc. 2d 974 (Sup. Ct., Suffolk Co. 1976) (permitting patient to refuse blood transfusion, despite uterine hemorrhaging); *Matter of Cray*, N.Y.L.J. Apr. 17, 1975, p. 15 (Sup. Ct., New York Co.) (upholding patient's refusal of hysterectomy); *Erickson v. Dilgard*, 44 Misc. 2d 27, 252 N.Y.S.2d 705 (Sup. Ct., Nassau Co. 1962) (recognizing patient's right to refuse blood transfusion, despite gastrointestinal bleeding). Significantly, the Court of Appeals relied upon *Erickson a Dilgard* in its *Eichner* and *Rivers* decisions as support for a common law right to refuse life-sustaining treatment.

9. *Eichner a Dillon*, 52 N.Y.2d at 377.

10. See *Matter of Application of Winthrop University Hospital*, 128 Misc. 2d 804, 490 N.Y.S.2d 996 (Sup. Ct., Nassau Co. 1985) (blood transfusion ordered for mother of two young children); *Matter of Application of Jamaica Hospital*, 128 Misc. 2d 1006, 491 N.Y.S.2d 898 (Sup. Ct., Queens Co. 1985) (blood transfusion ordered, over mother's objection, to save life of fetus); *Crouse Irving Memorial Hospital v. Paddock*, 127 Misc. 2d 101, 485 N.Y.S.2d 443 (Sup. Ct., Onondaga Co. 1985) (blood transfusion ordered, over mother's objection, to safeguard baby's life and health during cesarean delivery).

In *Randolph v. City of New York*, 117 A.D.2d. 44, 501 N.Y.S.2d 837 (1st Dept. 1986), the husband of a Jehovah's Witness sued physicians for *honoring* her refusal of blood transfusions, which resulted in her death. An appellate court rejected the husband's argument that the physicians were required to override his wife's decision because her death would have denied their children her support and caring. As the court stated, "The State's interest in assuring parental support is satisfied where there is a capable surviving parent." 501 N.Y.S.2d at 841.

11. *Matter of Delio*, N.Y.L.J., June 4, 1987, p. 1, col. 6 (App. Div., 2<sup>nd</sup> Dept.).
12. *Matter of Delio*, 134 Misc. 2d 206, 510 N.Y.S.2d 415 (Sup. Ct. Bronx Co. 1986).
13. *Matter of Delio*, N.Y.L.J., June 4, 1987, p. 34, col. 5.
14. *Id.*, p. 8, col. 4.
15. *Id.*, p. 35, col. 1.
16. *Workingmen's Circle Home and Infirmary for the Aged v. Fink*, 514 N.Y.S. 2d 893 (Sup. Ct., Bronx Co. 1987); *Matter of Chetta*, No. 1086 (Sup. Ct., Nassau Co., May 1, 1987); *Matter of Voael*, 512 N.Y.S. 2d 622 (Sup. Ct., Nassau Co., 1986). Cf. *Matter of Application of Kerr*, 517 N.Y.S. 2d 346 (Sup. Ct., New York Co. 1986) (acknowledging that artificial nutrition and hydration could be refused by a patient with capacity, but declining to permit withdrawal of treatment on ground that patient lacked capacity). In two cases, lower courts have denied petitions by nursing homes for authority to provide artificial nutrition and hydration to competent residents who refused to eat. *Matter of Brooks* (Sup. Ct., Albany Co. June 10, 1987); *Matter of Plaza Health and Rehabilitation Center* (Sup. Ct., Onondaga Co. Feb. 2, 1984). These two cases present the starkest questions about the scope of patient autonomy: the nursing home residents were neither terminally ill nor physically unable to eat.
17. *Brophy a New England Sinai Hospital, Inc.*, *supra*; *Hazelton v. Powhatan Nursing Home*, Chancery No. 98287 (Va. Cir. Ct., Fairfax Co. Sept. 5, 1986); *Rasmussen v. Fleming*, 2 CA-CIV 5622, (Ariz. Ct. App., Div. 2, June 25, 1986); *Corbett v. D'Alessandro*, 487 S.2d 368 (2d Dist. Fla. 1986); *Bouvia v. Superior Court*, *supra*; *Matter of Conroy*, *supra*.
18. E.g., *Brophy*, *supra*, 497 N.E.2d at 636; *Conroy*, *supra*, 486 A.2d at 1233-37.
19. See discussion. nn. 23-25.
20. E.g., *Matter of Application of Kerr*, *supra* (court declared patient incompetent and directed artificial nutrition by gastrostomy tube over patient's objections); *Matter of Harvey "U"*, 116 A.D.2d 351, 501 N.Y.S.2d 920 (court upheld finding that patient lacked capacity and directed amputation of patient's feet over his objection). *vacated as moot*, 68 N.Y.2d 624, 505 N.Y.2d 70 (1986); *Harris v. Roberts*, 91 A.D.2d 1141, 458 N.Y.S.2d 719 (3d Dept. 1983) (patient found incompetent to make rational treatment decision and treated for tuberculosis over her objection).

21. Judicial determinations of capacity to make health care decisions are most commonly rendered in proceedings commenced by health care facilities for authorization to administer treatment over a patient's objection. E.g., *Matter of Harvey "U"*, *supra*; *Harris v. Roberts*, *supra*; *Hanes v. Ambrose*, *supra*; *Matter of Ellis Hospital*, (Sup. Ct., Schenectady Co. Dec. 13, 1984); *University Heights Nursing Home v. Weidman*, No. N685 (Sup. Ct., Albany Co., Sept. 22, 1983); *Matter of Roosevelt Hospital*, *supra*; *New York Health and Hospitals Corp. v. Stein*, 70 Misc. 2d 944, 335 N.Y.S.2d 461 (Sup. Ct., New York Co. 1977); *Application of Long Island Jewish-HH'side Medical Center*, 78 Misc. 2d 395, 342 N.Y.S.2d 356 (Sup. Ct., Nassau Co., 1973). The capacity of a person to make health care decisions has also been judicially determined in competency proceedings or conservatorship proceedings pursuant to New York Mental Hygiene Law articles 77 and 78. But see Dale Moore, "The Durable Power of Attorney as an Alternative to the Improper Use of Conservatorship for Health Care Decision making," 60 *St. John's L. Rev.* 631 (criticizing the use of conservatorship proceedings to determine a person's capacity to make health care decisions). For residents of certain mental health facilities, Article 80 of the Mental Hygiene Law prescribes a special process to determine capacity to make specific health care decisions. A committee of volunteers, comprised of physicians and community representatives, is authorized to determine the resident's decisionmaking capacity and to make health care decisions on behalf of residents who are determined to lack capacity and who do not have family members available and willing to act on their behalf.

22. *Rivers v. Katz*, 67 N.Y.2d at 81, *Matter of Harvey "U"*, 501 N.Y.S.2d at 921.

23. E.g., *Matter of Harvey "U"*, *supra*; *Matter of O'Brien*, *supra*.

24. See *Matter of Harvey "U"*, 501 N.Y.S.2d at 922; See generally, President's Commission, *Making Health Care Decisions*, Vol. 2, p. 171, A. Meisel, "Exceptions to the Informed Consent Doctrine," *supra*, at 445-46. In some cases, however, it is apparent that the court's finding of capacity was based primarily on its evaluation of the patient's decision. E.g., *Matter of Application of Kerr*, *supra*.

25. The Task Force asked long-term care facilities in New York State, "How many residents in your nursing home had been adjudicated incompetent as of October 1, 1986?" There were 167 responses. The average response for facilities with less than 50 beds was that 1.4 residents had been adjudicated

incompetent; for facilities with 50-99 beds and those with 100-199 beds, there was an average of 2.4 persons adjudicated incompetent; and for facilities with over 200 beds, there was an average of 3.0 persons adjudicated incompetent. See Appendix B, Table D, p. 173.

26. E.g., *In re Quinlan*, 355 A.2d at 664; *Saikewicz*, 370 N.E.2d at 429-32 (1977); *Severns v. Wilminaton Medical Center*, 421 A.2d 1334, 1347 (Del. 1980); *John F. Kennedy Hospital v. Bludworth*, 452 So.2d 921, 926 (Fla. 1983); *Matter of Welfare of Colyer*, 660 P.2d at 741; *Matter of Conservatorship of Torres*, 357 N.W.2d at 337-38; *In re L.H.R.*, 321 S.E.2d at 722-23; *Barber v. Superior Court*, 195 Cal.Rptr. at 492-93; *Foody v. Manchester Memorial Hosp.*, 40 Conn. Sup. 127, 482 A.2d 713, 720 (1984).

27. *Matter of Storar and Eichner v. Dillon*, 52 N.Y.2d 363, 438 N.Y.S.2d 266, 420 N.E.2d 64, *cert. denied*, 454 U.S. 858 (1981).

28. *People v. Eulo*, 63 N.Y.2d 341, 357, 482 N.Y.S.2d 436, 446, 472 N.E.2d 286 (1984).

29. *Matter of Delio*, *supra*, N.Y.L.J., June 4, 1987, p. 1, col. 6 (App. Div., 2nd Dept.)

30. *Matter of Triarsi*, N.Y.L.J., Sept. 18, 1986, p. 12 (Sup. Ct., Suffolk Co. August 21, 1986).

31. *In re Moschella*, N.Y.L.J., May 22, 1984, p. 12 (Sup. Ct., Nassau Co.).

32. *Application of Lydia E. Hall Hospital*, 116 Misc. 2d 477, 455 N.Y.S.2d 706 (Sup. Ct., Nassau Co. 1982).

33. *Saunders v. State*, 129 Misc. 2d 45, 492 N.Y.S.2d 510 (Sup. Ct., Nassau Co. 1985). See discussion of *Saunders*, p. 76. *Cf. A.B. v. C.*, 124 Misc. 2d 672, 477 N.Y.S.2d 281 (Sup. Ct., Schenectady Co. 1984) (dismissing woman's petition to order a hospital to honor her living will on ground that court could not render an advisory opinion for a possible future treatment dispute.)

34. *Matter of Essner*, No. 21748 (Sup. Ct., Bronx Co. Dec. 17, 1986).

35. *Id.*

### **III. The Ethical Dilemmas of Foregoing Treatment**

#### **Refusing Treatment**

The emergence of a body of judicial decisions about life-sustaining treatment in the ten years following the *Quinlan* case does not diminish the need for informed debate and the formulation of policies to address the many issues left unresolved by judicial precedents. Deliberation about these issues will deepen our understanding of the underlying ethical concerns and obligations. Moreover, while in some instances public discussion will clarify the basis for real differences, it is also essential to forge agreement on fundamental principles. Without this agreement, our society will be unable to fashion policies responsive to the challenges and dilemmas medical advances continually present.

Since the *Quinlan* case first received national attention, the debate about life-sustaining treatment has focused on the conflict between two basic values: the preservation of human life and the autonomy of the individual. While other important values, such as other persons' interests in the patient's life and the integrity of the medical profession are also involved, the heart of the controversy has centered on the need to balance a commitment to preserve life with respect for the individual's right to control decisions about his or her own dying process.

As a society, we have long cherished both individual autonomy and the preservation of human life. Where those values are in conflict, however, our social pluralism embraces a range of responses. That pluralism is reflected in the diversity of individual moral decisions as well as the beliefs of different religious communities.

The religious denominations that have addressed issues related to life-sustaining treatment have all affirmed the sanctity of human life.<sup>1</sup> However, they posit different conceptions of the individual's obligation to accept treatment and the limitations of that obligation.<sup>2</sup> As set forth in the Vatican Declaration on Euthanasia, the Catholic Church teaches that a person has no obligation to accept "extraordinary" means to preserve his or her life.<sup>3</sup> Recognizing the potential vagueness of the term, "extraordinary," and the preference of some for a standard of proportionality, the Declaration stated that,

[o]ne cannot impose on anyone the obligation to have recourse to a technique which is already in use but which carries a risk or is burdensome. Such a refusal is not the equivalent of suicide; on the contrary, it should be considered as an acceptance of the human condition, or a wish to avoid the application of a medical procedure disproportionate to the results that can be expected, or a desire not to impose excessive expense on the family or the community.<sup>4</sup>

Many Protestant denominations also teach that a person may refuse life-sustaining measures that will only prolong the dying process.<sup>5</sup> The principles they articulate stress the importance of individual choices concerning treatment.<sup>6</sup> For example, a statement by the Presbyterian Church in 1983, entitled “The Covenant of Life and the Caring Community,” endorsed the importance of respecting the person’s wishes about treatment:

In a pluralistic society where people have different beliefs about life and death, basic Christian respect for persons demands that a person’s decisions about death be honored in most instances.<sup>7</sup>

The Methodist Church, in its statement on the issue, expressly affirmed “the right of everyone to die in dignity....”<sup>8</sup>

Among Protestant theologians, however, there is a diversity of opinion about the parameters of the moral obligation to accept treatment. For instance, one prominent Protestant theologian, Paul Ramsey, rejects quality of life judgments while another, Joseph Fletcher, advocates an ethic that focuses on the person’s experience of pain or discomfort.<sup>9</sup>

The Reform Jewish tradition also teaches that a person is not obligated to accept life-sustaining treatment that prolongs the dying process.<sup>10</sup> There is a spectrum of belief within the Conservative Jewish community ranging from a recognition that a person may refuse measures that unnecessarily prolong the dying process to a belief that a person must accept all measures that sustain life.<sup>11</sup>

Most Orthodox Jewish scholars interpret Jewish Law to require the acceptance of all treatment that will preserve every possible moment of life unless the patient is very near the moment of death.<sup>12</sup> Under Orthodox Jewish precepts, the patient’s preferences and the physician’s judgments are dictated by their obligation to God set forth in the “Halakhah” or Jewish law.<sup>13</sup> As stated by one eminent Orthodox Jewish scholar:



Judaism has always taught that life, no less than death is involuntary. Only the Creator who bestows the gift of life may relieve man of that life even when it has become a burden rather than a blessing."

The Task Force believes that all policies about life-sustaining treatment must affirm the value of life and the presumption in favor of continued treatment. However, where that presumption conflicts with the individual's preferences, the individual's right to decide about treatment must be respected. As long as the individual does not harm others or create a danger for the public, our society recognizes the freedom of each person to choose his or her own moral path. While we may seek to inform and shape the individual's sense of obligations to self and to others in the context of health care and other personal choices, in a pluralistic society, we cannot impose a single moral vision.

As a matter of principle, recognition of the person's right to make treatment decisions affirms the respect owed to all persons. On a practical level, one consequence of failing to recognize self-determination for health care choices is an acceptance of the use of force to override those choices. Presently, some health care facilities use both physical and chemical restraints, including tranquilizers and other powerful sedatives, when patients, even those who are competent, refuse treatment.

The Task Force believes that society should not condone the use of such restraints nor permit health care professionals, however strong their beliefs or beneficent their motives, to use force to provide treatment against the wishes of a competent patient. Although force is not necessary once patients have lost consciousness or the ability to resist or remove treatment, the heightened vulnerability of such patients creates special obligations to respect their moral choices. Continued treatment in these circumstances is no less an affront to their dignity because they are helpless to refuse treatment. Moreover, individuals should not be forced to relinquish their right to have their wishes about treatment honored when they lose decision-making capacity. The loss of such capacity is often marked by severe illness or, in some cases, the permanent loss of consciousness. It is precisely in such circumstances that persons might wish to have treatment withdrawn or withheld. For this reason, the opportunity to provide advance instructions and delegate the authority to someone else as a surrogate is crucial. Without this option, many people will effectively be denied the right to make decisions about their own dying process. They may receive less aggressive treatment than they

would want, or, in many instances, they may be treated in violation of their deeply held convictions.

Society does not lessen the value it places on human life by honoring the person's right to refuse treatment or by providing a vehicle to extend that right beyond the loss of decision-making capacity. Instead, it shows deep respect for the primacy of the individual's judgment and the choices the individual must make about the limitations and burdens imposed by illness.

Regard for autonomy, however, does not force society to abandon other values it deems fundamental. Society may still embrace and affirm other values central to medical delivery and to the community: the preservation of life; our human relatedness in the delivery of medical care and other spheres; and respect for our family traditions. These values may be expressed in our medical policies or the policies of society as a whole in the many social issues involving moral questions. We need not, therefore, as a community, place other moral goods and ideals at risk when we recognize autonomy.

Nor must we compel health care professionals to relinquish their own vision of their obligations to patients or their professional commitments. Where the patient's decisions conflict with the ethical beliefs of physicians or other health care professionals, a solution must be sought that respects the beliefs of all involved. That solution, as practiced now, often involves transferring care of the patient to other professionals or to other institutions. When the decisions of medical professionals and patients cannot be reconciled, health care providers should facilitate this alternative for mutual accommodation so that the moral choices of both patients and health care professionals may be honored.

### **Decisions About Artificial Nutrition and Hydration**

Of all the treatments considered by the Task Force in developing its recommendations, artificial nutrition and hydration was the focus of the most lengthy and thorough deliberation. The term "artificial nutrition and hydration" refers generally to the provision of food and water through tubes inserted in the patient's veins, nose and throat, stomach or intestine.

Artificial feeding is used to supplement nutritional intake or to provide total nutritional support on a short or long-term basis. As a long-term measure, artificial nutrition and hydration is usually provided through a tube inserted in the nose and esophagus or surgically inserted into the stomach or a portion of the small intestine.<sup>15</sup> While such nutritional support is generally

highly effective, potential complications, including the risk of serious infection, are numerous and vary according to the feeding method chosen.<sup>16</sup>

The issue of withdrawing artificial nutrition and hydration arises most frequently for patients who have permanently lost consciousness. It is also considered for some patients who are irreversibly ill and do not tolerate the procedure well.<sup>17</sup>

If artificial nutrition and hydration as well as other nursing and medical care are provided to patients who have permanently lost consciousness, their vital bodily functions may be maintained for many years.<sup>18</sup> Karen Ann Quinlan, for example, lived for ten years following removal of the artificial respirator that assisted her breathing. When artificial nutrition and hydration is withdrawn, patients usually die within a period of time ranging from two to ten days.<sup>19</sup>

Existing medical opinion suggests that patients who have permanently lost consciousness do not experience pain or discomfort following the withdrawal of artificial nutrition and hydration.<sup>20</sup> Less information is available about the experience of greatly debilitated patients or those suffering from severe illness who are in the end stage of the dying process. Available information, however, indicates that these patients appear to experience little, if any, discomfort when routine comfort measures are provided.<sup>21</sup> Finally, in some cases, the provision of artificial nutrition and hydration very close to the time of death may increase the patient's discomfort. Some patients are more likely to experience pulmonary edema, nausea and mental confusion when artificial nutrition and hydration are maintained in the last stages of the dying process.<sup>22</sup>

The public debate surrounding artificial nutrition and hydration often hinges on whether it should be distinguished from other medical treatment on moral and clinical grounds. Those who argue for the distinction generally believe that nutrition and hydration is basic care, not medical treatment.<sup>23</sup> Support for the distinction rests, in large part, on concerns about patients who lack decisional capacity and did not previously specify that they would want the treatment withheld. Proponents of the distinction point to the heightened vulnerability of patients who are unconscious or suffer from dementia, the incentives to discontinue nutritional support for such patients in a clinical environment concerned with cutting costs, and the possibility of undermining the bond of trust between patient and physician.<sup>24</sup>

While these concerns are obviously lessened or irrelevant in the context of decisions by competent patients to forego artificial

nutrition and hydration, other considerations raised by advocates for the distinction are germane. Those considerations relate primarily to the meanings associated with provision of nutrition and hydration and the effect on the broader community of permitting persons to die by starvation and dehydration.<sup>25</sup> Specifically, the provision of artificial nutrition and hydration is seen as an important symbol of our human relatedness and commitment to care for all members of the human community.<sup>26</sup> According to this view, nutrition and hydration, whether provided directly or by artificial means, are universal needs, not just needs of the sick.<sup>27</sup>

It is also suggested that permitting the withdrawal of artificial nutrition and hydration will blur the psychological distinction between allowing to die and active assistance to cause death.<sup>28</sup> Proponents of this position contend that the withdrawal of artificial nutrition and hydration is different from the withdrawal of other life-sustaining measures because of its certainty. Death is inevitable if nutrition and hydration are withheld, while death does not always occur following cessation of other treatments such as artificial respiration. Responsibility for the patient's death is therefore seen as more "direct."

In contrast, many believe that artificial nutrition and hydration is medical treatment, not basic care. This position is reflected in a March, 1986 statement by the American Medical Association's Council on Ethical and Judicial Affairs, recent court decisions and other public commentary.<sup>29</sup> In April 1987, the New York Academy of Medicine issued a statement which recognized that "technologically supplied nutrition or hydration" should not be distinguished from other life-sustaining treatments, and supported the right of competent patients to decline such measures.<sup>30</sup>

Advocates of this position believe that the withdrawal of artificial nutrition and hydration is no different ethically or medically from the withdrawal of other life-sustaining measures. They point out that the withdrawal of other treatment, such as dialysis or artificial respiration, also leads to the patient, and demands surgical intervention in some cases.<sup>31</sup> Proponents of this position recognize that nutrition and hydration provide without medical intervention are basic needs. They assert, however, that air, provided by artificial respiration, is an equally universal human need and cannot be distinguished.<sup>32</sup>

Among those who reject the distinction between artificial nutrition and hydration and other treatment, some advocate that, like other treatment, artificial nutrition and hydration cannot and should not be imposed over the wishes of a competent patient.<sup>33</sup> Others focus on the standard of proportionality and maintain that a competent patient may appropriate course of medical treatment.<sup>35</sup>

While the Task Force recognizes the human significance of providing artificial nutrition and hydration, and the emotional impact its withdrawal entails for some health care professionals, it believes that these concerns do not outweigh the right of a competent adult to have his or her wishes honored. In the vast majority of cases, the decision to forego artificial nutrition and hydration, whether the patient or by an appointed agent, will occur in circumstances where the patient is permanently unconscious or at the end stage of the dying process.

The Task Force recognizes that the issue may arise in other contexts, as it did in the case of Elizabeth Bouvia, a 28-year old quadriplegic woman with an extended life expectancy who refused artificial nutrition and hydration. Circumstances like the *Bouvia* case, while compelling both in terms of the personal tragedy and the clash of principles they present, are extremely rare. They undoubtedly will remain so and the Task Force believes that they should be resolved on an individual basis. In each case, the patient's decision may reflect complex social, psychological and personal circumstances. Those circumstances must be identified in the context of a dialogue that explores the financial, social, or medical support that could be provided to create more acceptable life options for the individual. For example, in the Bouvia case, Elizabeth Bouvia agreed to eat on her own when other concerns had been addressed. She also sought the opportunity to live at home, rather than in a public hospital facility.<sup>36</sup>

In any event, these cases are at the outer edges of our collective social and medical experience. They must not serve as a guide post to the formulation of public policy. The passions and concerns they

raise will distort the public debate about the issue and shift the focus away from the crucial question that must be addressed: how will society respect the wishes of those who would want artificial nutrition and hydration withdrawn to ease their dying process or to release them from continued unconscious existence without hope for recovery or cure?

Persons who believe that such wishes should always be denied often assert that accommodating these wishes would be the first step down a slippery slope toward euthanasia or the inappropriate withdrawal of treatment from persons in our society who are mentally disabled or otherwise especially vulnerable. According to this view, once the withdrawal of artificial nutrition and hydration is permitted under any circumstances, it will lead to the devaluation of human life and widespread abuse.

The Task Force believes that the right of competent adults to decide for themselves applies to decisions about the withholding and withdrawal of artificial nutrition and hydration. At the same time, it recognizes that the value of patient autonomy must be balanced with other important social concerns. In seeking to achieve this balance, society must move forward with caution and thoughtful concern.

## **Euthanasia**

The distinction between “killing” and “letting die” has been the subject of considerable debate. Although the debate is not new, the moral significance of the distinction has been criticized more frequently in recent years.

In this debate, the terminology used is often confusing. The word *euthanasia*, from the Greek, originally meant “a good death.” In our own time, however, it has been applied to the direct and painless killing of an incurably ill person seeking relief from a protracted dying process. Some authors distinguish between “active” or “positive” euthanasia and “passive” or “negative” euthanasia.<sup>37</sup> In this terminology, active or positive euthanasia refers to direct actions to end a patient’s life—i.e., taking positive steps to bring about death sooner than would otherwise be expected. “Passive euthanasia” encompasses the planned omission of treatment that would normally prolong the patient’s life. Some make a further distinction based on whether the omission of treatment is morally acceptable.<sup>38</sup> For the sake of clarity, the Task Force prefers to avoid the active- passive terminology and speak simply of “euthanasia” defined as measures to bring about the patient’s death, as distinct from the “withholding or withdrawal of life-sustaining treatment.”

Those who deny the moral distinction between euthanasia and the withdrawal or withholding of treatment focus on several factors.<sup>39</sup> They assert that the withdrawal of life-sustaining treatment cannot be distinguished in principle from affirmative steps to hasten a patient's death because the intent, motive and outcome are the same.<sup>40</sup> They point out that, in both cases, the person intends to cause the patient's death, acts out of compassionate motives, and causes the same outcome.<sup>41</sup> Some maintain that euthanasia can, in fact, be distinguished only in that it results in a more humane, less painful death.<sup>42</sup>

Others disagree strenuously and note that there is a long tradition of religious and moral wisdom that draws a line between the two practices.<sup>43</sup> They point out that the intention and nature of the actions in both cases are complex and are not essentially the same. In the one case, the person directly intends to cause death and uses the means at his or her disposal to achieve this end; in the other, the person arrives at a judgment that certain forms of treatment are not morally obligatory or medically appropriate and then directs that such treatment be withdrawn or withheld, accepting but not intending the person's death caused by the underlying illness.<sup>44</sup>

Advocates who support the distinction have also looked to practical considerations, including differences in the cause of death and the psychological distinction between action and omission.<sup>45</sup> Others assert that the difference is inextricably related to the ethos of medical practice and cannot be overcome without destroying the moral fabric of trust and respect for human life at the core of the physician-patient relationship.<sup>46</sup> Finally, some proponents of the distinction acknowledge that killing a person may be more humane than letting the person die, when the latter would result in a painful and prolonged dying process; they believe, however, that borderline, hard cases do not justify overturning the prohibition against the taking of human life.<sup>47</sup> Moreover, they focus on the potential consequences of removing the distinction and argue that the likelihood of abuse is too great when one human being is legally permitted to take the life of another.<sup>48</sup>

The Task Force strongly believes that existing laws prohibiting the taking of human life must not be modified. While the moral distinction between assisting to die and withdrawing treatment is hard to discern in certain cases, many Task Force members feel that there are compelling religious and moral grounds for the distinction. All the Task Force members believe that as a matter of public policy the taking of human life must not be granted legal sanction.

The prohibition against killing has deep roots in our religious, social and legal traditions. Prohibiting euthanasia affirms this tradition and preserves the conception of medicine as a healing profession. It also prevents the grave potential for abuse inherent in any law that sanctions the taking of human life.

If one human being is legally permitted to take the life of another, society will have changed its understanding of human life. It will no longer see each person as inviolable and will have embraced the assumption that one human being has the power of life over another.

The Task Force recognizes that euthanasia would provide a less painful, prolonged dying process for certain patients. Nevertheless, it believes that compassion for these patients and their plight cannot justify a change in public policy that will allow one human being to kill another.



## Footnotes

1. James Johnson, "History of Protestant Medical Ethics," *Encyclopedia of Bioethics*, Vol. 3 (New York: The Free Press, 1978). pp. 1364—73; Emmanuel Jakobovits, "Judaism," *Encyclopedia of Bioethics*, Vol. 2. pp. 791-802; Charles Curran, "Roman Catholicism," *Encyclopedia of Bioethics*, Vol. 4, pp. 1522-33.

2. *Id.*

3. Congregation for the Doctrine of the Faith, *Declaration on Euthanasia* (1980). See also. National Conference of Catholic Bishops, *Ethical and Religious Directives for Catholic Health Facilities* (Catholic Health Association of the United States, 1971).

In recent years, commentary on the Declaration has often focused on whether artificial nutrition and hydration are "extraordinary" treatment and may, therefore, be withdrawn or withheld if they are useless for the patient or result in a severe burden. Several prominent Catholic theologians have argued that artificial nutrition and hydration should be evaluated like other treatments under the framework set forth in the Declaration. See John Paris and Andrew Varga, "Care of the Hopelessly 111," *America*, Vol. 153, Sept. 22, 1984, pp. 141-44; Kevin O'Rourke. "The A.M.A. Statement on Tube Feeding: An Ethical Analysis," *America*, Vol. 155, No. 15, Nov. 22, 1986. pp. 321-23; James Walter, "Food and Water: An Ethical Burden," *Commonweal*, Vol. 113, No. 20, Nov. 21, 1986, pp. 616-22; Richard McCormick, "Caring or Starving: The Case of Claire Conroy," *America*, Vol. 152, No. 13, April 6, 1985, pp. 269-73. See also, Gerald Kelly. "The Duty of Using Artificial Means of Preserving Life," *Theol. Stud.*, Vol. 11, June 1950. Although it was written in 1950, prior to the issuance of the Vatican Declaration, Kelly's article proposes that artificial means to prolong life, including intravenous feeding, may be discontinued for patients who have permanently lost consciousness. Walter, Paris, McCormick and O'Rourke maintain that an assessment of the burden imposed by the provision of artificial nutrition and hydration should focus on the burden or discomfort caused by the treatment. They also assert that continued biological existence should not be evaluated as an end in itself, but as a precondition for the attainment of spiritual and personal goals.

In a statement of guidelines for legislation on life-sustaining treatment, the United States Bishops' Committee for Pro-life Activities urged that laws about life-sustaining treatment should establish a strong presumption in favor of providing artificial nutrition and hydration but recognized that, "Laws dealing with medical treatment may have to take account of exceptional circumstances, when even means for providing nourishment may become too ineffective or burdensome to be obligatory." United States Bishops' Committee for Pro-Life Activities, "The Rights of the Terminally 111," *Origins*, Vol. 16, No. 12, Sept. 4, 1986, pp. 222-24.

In contrast to this position, the Catholic Conference in New Jersey has stated that artificial nutrition and hydration are “basic care” that should always be provided. In assessing the benefits and burdens of providing artificial nutrition and hydration to permanently unconscious patients, the Conference maintained, “There is no dispute that nutrition and hydration are beneficial because they would preserve the permanently unconscious patient’s life. Nor can it be said that the care involved in feeding is burdensome to the permanently unconscious patient.” Brief for Amicus Curiae New Jersey Catholic Conference at 7, *Matter of Jobes*, No. 26,041 (N.J.) (appeal argued Nov. 5, 1986, decision pending). For a critique of this position, see John Paris and Richard McCormick, “The Catholic Tradition on the Use of Nutrition and Fluids,” *America*, Vol. 156, No. 17, May 2, 1987, pp. 356-61. See also, Robin Topping, “Theologian Supports Woman’s Right to Die,” *Newsday*, Feb. 19, 1987, p. 2; Robin Topping, “Theologian Barred in Right to Die Trial,” *Newsday*, Feb. 20, 1986, p. 4; Richard Ostling, “Is It Wrong to Cut Off Feeding?” *Time*, Feb. 23, 1987, p. 71.

4. Congregation for the Doctrine of the Faith, *Declaration*. For further discussion of the Catholic perspective on foregoing life-sustaining treatment, see Donald McCarthy and Edward Bayer, *Handbook on Critical Life Issues* (St. Louis: Pope John Center, 1982), pp. 159-69; Richard McCormick, *Health and Medicine in the Catholic Tradition* (New York: Crossroads 1984); United States Bishop’s Committee for Pro-Life Activities, 1985, pp. 222-24.

5. Johnson, pp. 1364-73.

6. *Id.*

7. General Assembly of the Presbyterian Church, *The Covenant of Life and the Caring Community* (July 1983).

8. General Council of the Methodist Church, *Death With Dignity* (1980).

9. Paul Ramsey stresses that it is immoral to choose death as an end, since life is a gift from God: “Still, worthy or unworthy, we remain trustees making choices among the goods of life, and we do not lay claim to dominion, co-dominion, or co-regency over human life itself.” Although Ramsey acknowledges that a competent patient may use a quality of life standard in making decisions about life-sustaining treatment, he does not endorse it. *Ethics at the Edges of Life* (New Haven: Yale University Press, 1978), pp. 146, 154-55.

In contrast, Joseph Fletcher advocates an ethic that focuses on the quality of life, arguing that “the well-being of persons” is “the highest good.” Fletcher not only believes that an individual may choose death as an end, but also supports the provision of active assistance to die to

relieve the suffering of a dying person. *Humanhood: Essays in Biomedical Ethics* (Buffalo: Prometheus Books, 1979), pp. 149-58.

10. Personal conversation with Rabbi A. James Rudin, National Director of Interreligious Affairs, American Jewish Committee, April 24, 1987.

11. Rabbi Seymour Siegel, Testimony before the New York State Assembly and Senate Health Committees, Public Hearing on Legislation Regarding the Issuance of Do Not Resuscitate Orders, Feb. 12, 1987, Transcript, pp. 301-05; Personal communication with Rabbi David Feldman, October 8, 1986.

12. J. David Bieich. "The Obligation to Heal in the Judaic Tradition," in *Jewish Bioethics*, Fred Rosner and J. David Bieich (eds.) (New York: Hebrew Publishing Company, 1979), pp. 17-20; Emmanuel Jakobovitz, *Jewish Medical Ethics* (New York: Bloch, 1959), pp. 119—25; David Feldman and Fred Rosner, *Compendium on Medical Ethics* (New York: Jewish Philanthropies of New York, sixth ed., 1984), pp. 100-03.

13. *Id.*

14. J. David Bieich. "The Quinlan Case: A Jewish Perspective," in *Jewish Bioethics*, p. 269.

15. C. M. Lewis, *Nutrition and Nutritional Therapy in Nursing*, (Norwalk, CT: Appelton Century-Crofts, 1986). Total parenteral nutrition (TPN) is another means of artificial feeding that involves the provision of nourishment through a central venous catheter. The risks and high cost of TPN, however, make tube feeding the treatment of choice for most patients who can process food in some portion of their gastrointestinal tract. See John Rombeau and Michael Caldwell, "Enteral Tube Feeding at Home," in *Clinical Nutrition*, Vol. 1, Catherine Bastian and Richard Driscoll, (eds.) (W. B. Saunders Co., 1984), pp. 494-512; Sonia Chrysomilides and Mitchell Kaminiski, "Home Enteral and Parenteral Nutritional Support: A Comparison," *Am.J.Clin. Nutr.*, Vol. 34, Oct. 1980, pp. 2271-75.

16. For a detailed discussion of the potential complications and side effects associated with different methods of providing artificial nutrition and hydration, see Marie Bernard and Loretta Forman. "Complications and Their Prevention," in *Clinical Nutrition*, Vol. 1, pp. 542-69.
17. Joanne Lynn and James Childress. "Must Patients Always Be Given Food and Water?" *Hast.Ctr.Rpt*, Vol. 13, No. 4, Oct. 1983, pp. 17—21; Phyllis Schmitz and Merry O'Brien, "Observations on Nutrition and Hydration in Dying Cancer Patients," in *By No Extraordinary Means*, Joanne Lynn (ed.) (Bloomington: Indiana University Press, 1986) pp. 29-38.
18. See p. 17, n. 3.
19. Conversation with Fred Plum, M.D., Chairman, Dept. of Neurology, Cornell-New York Hospital Medical Center, April 15, 1987.
20. See p. 17, n. 1. In describing the basis for decisions about treatment for permanently unconscious patients, the President's Commission stated, "Thus, treatment ordinarily aims to benefit a patient through preserving life, relieving pain and suffering, protecting against disability, and returning maximally effective functioning. If a prognosis of permanent unconsciousness is correct, however, continued treatment cannot confer such benefits." President's Commission, *Deciding to Forego Life-Sustaining Treatment*, p. 181.  
 Ronald Cranford has written several articles concerning the most common form of permanent unconsciousness, the "persistent vegetative state." In "Termination of Treatment in the Persistent Vegetative State," he points out that, "One reservation that some have about stopping fluids and nutrition involves the suffering associated with starvation and dehydration. From a medical standpoint, this is not true of PVS. These patients are not capable of being aware of starvation and dehydration." *Seminars in Neurology*, Vol. 4, No. 1, March 1984, p. 151. See also, Brief for Amicus Curiae American Academy of Neurology at 10-29, *Brophy v. New England Sinai Hospital*, 398 Mass. 417, 497 N.E. 2d 626 (1986).
21. Schmitz and O'Brien, pp. 29-38; J. Andrew Billings, "Comfort Measures for the Terminally Ill: Is Dehydration Painful?" *J.Am.Ger. Soc.*, Vol. 33, No. 11, Nov. 1985, pp. 808-10. Billings reports that the only troubling and commonly encountered symptoms that can be attributed to dehydration in terminally ill patients are thirst and dry mouth. He suggests that

these symptoms can be relieved by small amounts of oral fluid or by keeping the patient's mouth moist with water, ice chips or artificial saliva. See also, "Terminal Dehydration," (editorial) *Lancet*, No. 8-170, Feb. S. 11)8(5, p. 306; David Oliver. "Terminal Dehydration." (letter) *Lancet*, No.8403, Sept. 15, 1984, p.631

22. Lynn and Childress, p. 19.

23. Gilbert iVleilaender, "On Removing Food and Water: Against the Stream," */fast. (It: Rpt.*, Vol. I t, No. 0, Dec, 108-1. pp. 11-13; Patrick Derr, "Why Food and Fluids Can Never Be Denied," *Hast.Ctr.Rpt.*, Vol. 16, No. I, Feb. 108(5. pp. 28-30; Daniel Callahan, "Feeding the Dving Elderly," *(fenerations*, Vol. 10, No. 2, Winter 1085, pp. 15-17; Alan Weisbard and Mark Siegler "On Killing Patients with Kindness: An Appeal for Caution," in *fiv AM Extraordinary Means*, pp. 108-1(5: Brief for Amicus Curiae New Jersey Catholic Conference at 7, *Mutter of Jobes*, No. 2(5, 041 (N.J.) (appeal argued Nov. 5, 1986, decision pending),

24. See n, 2.3

25. Weisbard and Siegler, pp. 111-12; Derr, p. 30.

26. As stated try Weisbard and Siegler, "Although the techniques (or providing such supports may he medical, and thus logically associated with other medical interventions, the underlying obligations of providing food and drink to those who hunger or thirst transcend the medical context, summoning up deep human responses of caring, of nurturing, of human connectedness, and of human community," p. 112. See also, Meilaender, pp. 11-13; Callahan, pp. 16-17.

27. Derr, p. 29; .Meilaender, pp. 12-13.

28. Weisbard and Siegler, p. 113; Meilaender, pp. 11-13; Derr, pp. 28-30,

29. In a statement addressing the standards for decisions about withholding and withdrawing life-sustaining treatment, the AMA Council on Ethical and Judicial Affairs recognized that artificial nutrition and hydration should be evaluated according to the same standards as other life-sustaining measures. "Life-prolonging medical treatment includes medication and artificially or technologically supplied respiration, nutrition or hydration. In treating a terminally ill or irreversibly comatose patient, the physician should determine whether the benefits of treatment outweigh its burdens." American Medical Association, Council on Ethical and Judicial

Affairs, "Withholding or Withdrawing Life Prolonging Medical Treatment," (Mar. 14, 1986). See -9.su, Lynn and Childress, pp. 1-19; t ieorge Annas, "Do Feeding Tubes Have More Rights than Patients?" *Hast.Ctr.Rpt.*, Vol. 16, No. 1, Feb. 1986, pp. 26-28; Sidney Wanzer, et al., "The Physician's Responsibility Toward Hopelessly 111 Patients," *NEJM*, Vol. 310, No. 15, pp. 955-59.

30. "Statement of the Joint Subcommittee on the Care of the Terminally 111 of the Committee on Public Health and the Committee on Medicine in Society," approved by the Council of the New York Academy of Medicine, April 22, 1987.

31. Annas, pp. 28-30; Lynn and Childress, pp. 17-19.

32. Annas, p. 28; McCormick, p. 270.

33. Annas, p. 27; James Childress, "When Is It Morally Justifiable to Discontinue Medical Nutrition and Hydration?" in *By No Extraordinary Means*, pp. 67—83; Dan Brock and Joanne Lynn, "The Competent Patient Who Decides Not to Take Nutrition and Hydration," in *By No Extraordinary Means*, pp. 202-15.

34. John Paris espouses this view in "When Burdens of Feeding Outweigh Benefits," *Hast.Ctr.Rpt.*, Vol. 16, No. 1, Feb. 1986, pp. 30-32. He also attributes it to Gerald Kelly *Theol Stud.*, June 1980. See also, James Walter, "Food and Water: An Ethical Burden," *Commonweal*, Nov. 21, 1986, pp. 616-19.

35. Brock and Lynn, pp. 202-15; Annas, pp. 26-28.

36. George Annas, "Elizabeth Bouvia: Whose Space Is This Anyway?" *Hast.Ctr.Rpt.*, Vol. 16, No. 2, April 1986, pp. 24-25. In this discussion of the Bouvia case, Annas argues that society failed to provide Elizabeth Bouvia with the funds necessary to allow her to live independently with appropriate medical and nursing care.

37. See, e.g., Bernard Haring, *Medical Ethics*, (Notre Dame: Fides, 1973), pp. 144-45.

38. Congregation for the Doctrine of the Faith, Declaration.

39. James Rachels, "Active and Passive Euthanasia," *NEJM*, Vol. 29, No. 2, Jan. 9, 1975, pp. 78-80; Michael Tooley, "Abortion and Infanticide," *Phil. & Pub.Aff.*, Vol. 2, No. 1, 1972, pp. 37-65. See also, James Rachels, *The End of Life* (New York: Oxford University Press, 1986), pp. 106-28; Fletcher, pp. 149-158; Tristram Engelhardt, *The Foundations of Bioethics* (New York: Oxford University Press, 1986), pp. 301-20.

40. Rachels, pp. 78-80; Tooley, pp. 37-65.
41. *Id.*
42. Fletcher, pp. 149-158.
43. E.g., Gilbert Meilander, "The Distinction Between Killing and Allowing to Die," *Theol.Stud.*, Vol. 37, 1976, pp. 468-69.
44. See Haring, pp. 140-144.
45. Veatch, pp. 80-98. Veatch examines the moral implications of five potential differences between the intended termination of life and the withholding of treatment: (i) the psychological differences between actions of omission and actions of commission; (ii) the conflict between active killing and the physician's role as healer; (iii) the differences of intent; (iv) the differences in the cause of death; and (v) the different consequences or potential for abuse. He concludes that these distinctions, taken together, support a moral difference between active killing and the withdrawal of treatment, but acknowledges that each distinction fails to provide sufficient justification when it stands alone.
46. Childress, pp. 128-31.
47. Thomas Beauchamp, "A Reply to Rachels on Active and Passive Euthanasia," in *Ethical Issues in Death and Dying* Thomas Beauchamp and Seymour Perlin (eds.) (New Jersey: Prentice Hall, 1978) pp. 246-58; Charles Fried, "Rights and Health Beyond Equity and Efficiency," *NEJM*, Vol. 29, July 31, 1975, p. 245.
48. Beauchamp, pp. 246-58.





# Minority Report

## Patient Autonomy and Societal Interests J. David Bleich

We believe these Truths to be self-evident, that all men are created equal, that they are endowed by their Creator with certain unalienable rights, that among these are Life, Liberty and the Pursuit of Happiness.

—Declaration of Independence

The “unalienability” of which the Founding Fathers of this country spoke refers not simply to a lack of capacity on the part of any person or power to deprive man of any of these fundamental rights, but also to self-alienation of such rights by the individual himself. These rights are inherent in the moral condition of mankind and hence man can no more divest himself of those rights than he can divest himself of his humanity. Since freedom is inalienable, a contract providing for the enslavement of an individual is null and void *ab initio*. The British philosopher Thomas Hobbes similarly argued that a contract requiring an individual not to thwart the taking of his life even when that life becomes forfeit through due process of law, e.g., by means of execution as punishment for a crime, is devoid of either legal or moral significance.<sup>1</sup> The right to life is of paramount moral significance and simply cannot be limited or encumbered.

Common law categorized alienation of the right to life as a crime — the crime of homicide. Criminalization of *felo-de-se*, i.e., suicide, was formalized in England by King Edgar in the year 967.<sup>2</sup> In the middle of the thirteenth century, Henry de Bracton, the first English legal writer to discuss suicide, wrote that self-destruction is analogous to murder: “Just as a man may commit felony by slaying another so may he do so by slaying himself.”<sup>9</sup> Thus, abnegation of one’s own right to life, viz., suicide, was regarded as indistinguishable from murder at common law. Since it was a crime, suicide had to be punished even though the criminal had effectively removed himself from the pale of the law. Since execution was impossible (and even if feasible, execution would hardly have been regarded as an appropriate punishment or have served as a deterrent) the prescribed punishment consisted of (1) denial of burial rights and of interment in consecrated ground; (2) branding the body with “marks of ignominy,” e.g., a stake driven through the body and a stone placed over the corpse which was then buried at a cross-roads; and (3) forfeiture of goods and

chattels.<sup>4</sup> Although comparable sanctions were never widely adopted in this country, nevertheless, at least three states still consider suicide a crime or an immoral act.<sup>5</sup> Some states forbid attempted suicide<sup>6</sup> while criminal sanctions under case or statutory law for aiding and abetting suicide are widespread and exist in the vast majority of states.<sup>7</sup>

The law ascribes criminal liability for causing the death of another not only when an overt act of aggression is involved but also when death is the result of withholding the necessities of life, e.g., food, drink, or medication. Thus, in *Commonwealth v. Korn?*, a woman was held criminally liable for removing insulin from a refrigerator, hiding it and thereby causing the death of her diabetic husband. Similarly, suicide, although primarily a crime of commission, can at times be committed by means of an act of omission. This principle was clearly affirmed by a New Hampshire court several years ago.<sup>9</sup> It follows that suicide, the crime of *felo-de-se*, is attendant upon causing one's own death by starvation or dehydration. Criminal sanctions provided by law for aiding and abetting a suicide would similarly apply in instances of passive suicide.

### **Suicide and Personal Autonomy**

The classification of suicide as a felony in common law may appear to be antithetical to the common law right to bodily self-determination as well as the recently developed notion of a constitutionally protected right to privacy. The classic and frequently quoted formulation of the self-determinism doctrine is that of Justice Benjamin N. Cardozo in *Schloendorff v. Society of New York Hospital*:<sup>10</sup>

In the case at hand the wrong complained of is not merely negligence. It is trespass. Every human being of adult years and sound mind has a right to determine what shall be done with his own body; a surgeon who performs an operation without his patient's consent commits an assault, for which he is liable in damages."

There is, to be sure, a fundamental tension between an individual's right to liberty and the denial of his right to terminate his own life. Perhaps the simplest resolution of that dilemma is suggested by the philosopher most intimately associated with advocacy of liberty and personal autonomy, John Stewart Mill. In his essay *On Liberty*, Mill argues that commission of an act which forecloses any future enjoyment of liberty beyond that single act cannot be justified on libertarian

grounds. In selling himself as a slave a person abdicates his liberty. Hence, argues Mill, the principle of freedom cannot require that a person should be free not to be free: "It is not freedom to be allowed to alienate...freedom."<sup>11</sup> A person cannot invoke a right to liberty as justification for being permitted to dispose of his own life. Liberty cannot exist as a transcendental ideal: liberty is meaningful only as an attribute of a subject. Destruction of a human life is *ipso facto* destruction of all the attributes of that life. Hence, to uphold the right to suicide in the name of liberty is illusory and even selfcontradictory for it assimilates into an argument for the right to invoke liberty the means to abrogate and extinguish that very same liberty. There is indeed an inherent irony in a claim of a right to destroy the life from which all rights flow."

Of direct legal significance is the fact that the liberty given constitutional protection by the Fourteenth Amendment is by no means absolute. Governments retain powers of sovereignty vaguely termed "police powers" relating to the safety, health, morals and general welfare of the public. Enjoyment of both property and liberty are subject to such reasonable conditions as may be imposed by the State in the exercise of its police powers. Courts have long recognized that the Fourteenth Amendment was not designed to interfere with the exercise of such powers.<sup>14</sup>

The interest of the State in preventing suicide was first articulated in a sixteenth-century British case, *Hales a Petit.* In his decision in *Hales*, Justice Dyer enumerated a number of different and diverse objections to suicide. For purposes of American jurisprudence the crucial consideration is that suicide is "[a]gainst the King in that hereby he has lost a subject...one of his mystical members."<sup>15</sup> Suicide may be prevented—and punished—by the King because it constitutes interference with his rights as monarch. The notion that suicide constitutes interference with the prerogatives of the monarch was accepted by Blackstone who, in his *Commentaries*, states that "[T]he suicide is guilty of a double offense; one spiritual in evading the prerogative of the Almighty and rushing into his immediate presence uncalled for; the other temporal, against the King, who hath an interest in the preservation of all his subjects...."<sup>17</sup> The common law notion of preservation of life as a monarchical prerogative has been transformed in American legal theory law into an inherent function of government. Thus Thomas Jefferson wrote, "[T]he care of human life and happiness, and not their destruction, is the first and only legitimate object of good government."<sup>14</sup> In an early American case,

a Massachusetts court noted that “[t]he life of every human being is under the protection of the law and cannot be lawfully taken by himself, or by another with his consent, except by legal authority.”<sup>19</sup>

The function and purpose of government is the ordering of a social structure in which individuals may maximally achieve their desires and aspirations. In order to exercise their rights in achieving those goals, members of society permit other rights to be limited or curtailed to the extent that it becomes necessary to do so in order to preserve the social fabric without which all rights are rendered meaningless and nugatory. Prevention of suicide, even by force if necessary, is rooted in the firmly established doctrine that individual rights, whether rooted in common law or constitutionally guaranteed, may be abrogated in the face of a countervailing state interest.

The State interest in preventing suicide is multi-faceted but clearly definable. The decision in *Hales* posited a monarchical interest in not being deprived of an economically functioning individual. To phrase the same concept in other terms: a suicide has already taken full advantage of the benefits bestowed by the community but seeks to shirk his own duties to the same community. The State enjoys an interest in the productivity of each of its citizens; only by assuring his or her life and well-being can the State reap the benefits of that person’s labor. A closely parallel interest is the State’s need of healthy citizens to assure its security and defense. Although earlier common law sources fail to declare explicitly the King’s interest as lying in a need for citizens to serve in his armies or in a need for their services as procreators of soldiers to defend the realm, one New York decision declares that the State interest in preserving the life of each of its citizen is associated, *inter alia*, with its need for citizens capable of bearing arms. Thus, in *People v. Carmichael*,<sup>1</sup> the court noted that it is in the interest of the State to have strong, robust, healthy citizens, capable of self-support, of bearing arms, and of adding to the resources of the country. Accordingly, the court held that legislation requiring the wearing of a protective helmet for the self-protection of motorcycle drivers was a valid purpose of legislative action under the police power of the State. In *State v. Congdon* a New Jersey court held that the state could impose criminal sanctions on individuals who refuse to take cover during an air raid drill, declaring that, “the basis of the State’s police power is the protection of its citizens. This protection must be granted irrespective of the fact that certain individuals may not wish to be saved or protected.”<sup>22</sup>

*Hales* identifies yet another State interest in declaring that suicide is an offense against the King in that “the King, who has the government of the people, [takes] care that no evil example be given them.”<sup>23</sup> Killing invites imitation; therefore, self-destruction serves as an “evil example” encouraging emulation by other susceptible members of society. Suicide “infringe[s] upon the King’s peace” because a suicide is not an isolated individual act.<sup>23</sup> The harm is not really to the King as an individual but constitutes an offense against society because of potential harm to others. If openly permitted, suicide diminishes commitment to the preservation of life and compromises the State’s interest in preserving respect for life which constitutes the fundamental underpinning of the social fabric.

There are indeed many limits upon an individual’s right to privacy and bodily autonomy based upon potential harm to others. The right to an abortion ceases at the beginning of the third trimester when the fetus becomes independently viable.<sup>25</sup> Despite the right of every individual to control his own person, there may be an exemption for intimate examination of a condemned woman to determine if she is pregnant in order to guard against the taking of the life of an unborn child for the crime of the mother.<sup>26</sup> A stop and frisk by policemen on the street may be reasonable despite the severe intrusion upon bodily security.<sup>27</sup> Similarly, a person may be forced to submit to a vaccination in order to protect the community from disease.<sup>28</sup> Likewise, a blood sample may be forcibly extracted from a person arrested for drunken driving.<sup>29</sup> Accordingly,

[I]t is evident that the right to privacy does not include the right to commit suicide....” Only personal rights that can be deemed “fundamental” or ‘implicit in the concept of ordered liberty...are included in this guarantee of personal privacy (*Roe v. Wade*, 410 U.S. 113, 152). To categorize a person’s self-destructive act as entitled to that constitutional protection would be ludicrous.<sup>30</sup>

The State’s power to prevent suicide is beyond question. Indeed, one case raising a constitutional challenge to an attempted suicide statute was dismissed for want of a substantial federal question.<sup>31</sup>

Given the fact that, as noted earlier, no distinction can be made between acts of omission and acts of commission with regard to either homicide or *felo-de-se*, so long as the State may assert a sufficiently compelling interest in preservation of the person in question, it may compel the patient to accept medical treatment

for the preservation of that life, at least when there can be no dispute regarding either the necessity or efficacy of the proposed treatment. As succinctly stated by Judge Skelly Wright in *In re President and Directors of Georgetown College*<sup>12</sup>:

[W]here attempted suicide is illegal by the common law or by statute, a person may not be allowed to refuse necessary medical assistance when death is likely to ensue without it. Only quibbles about the distinction between misfeasance and nonfeasance, or the specific intent necessary to be guilty of attempted suicide, could be raised against this latter conclusion.<sup>33</sup>

### **Limitations Upon the State's Power**

Although decisions of some courts in other states may perhaps be construed as having seriously eroded the State's right to prohibit suicide by means of refusing medical treatment, there is no decision in the State of New York which should be construed as establishing an absolute right to refuse treatment. Most courts have adopted an approach requiring the balancing of the State's interest against the right of every individual to autonomy vis-a-vis his own person. In a medical context, the balancing of those interests requires an assessment of factors such as longevity as well as assessment of the quality of life to be protected. Thus, in *In re Quinlan*,<sup>M</sup> the New Jersey Supreme Court declared,

We think that the State's interest *contra* weakens and the individual's right to privacy grows as the bodily invasion increases and the prognosis dims. Ultimately there comes a point at which the individual's rights overcome the State interest.<sup>35</sup>

The entirely cogent premise underlying the *Quinlan* approach is that, as stated in *Georgetown*, there is no fundamental distinction between refusal of medical treatment and refusal of other life-sustaining necessities and that freedom to refuse treatment is far from absolute. Hence, whenever the State's interest is deemed paramount, it must prevail over considerations of personal autonomy with the result that, when the State's interest in sustaining life of a particular quality is to be regarded as dominant, medical treatment may be commanded. Thus, in *In re Storar* although the New York Court of Appeals affirmed the right of a terminally ill patient to refuse treatment, it pointedly noted that such a holding should not be construed as an affirmation of a general right to terminate one's life.<sup>37</sup>

It is indeed true that in two New York cases the courts have refused to order treatment on behalf of competent adult patients who refused life-saving medical intervention despite the fact that, if successfully undertaken, the patients would have been restored to normal, healthy and productive lives. In *Erickson v. Dilgard*<sup>M</sup> the court refused to compel a patient to undergo a blood transfusion in conjunction with an operation for gastrointestinal bleeding, stating that "it is the individual who is the subject of a medical decision who has the final say and that this must necessarily be so in a system of government which gives the greatest possible protection to the individual in the furtherance of his own desire."<sup>39</sup> *Erickson* involved a situation in which a competent, conscious, adult patient was admitted to a county hospital suffering from intestinal bleeding. An operation was suggested, to be accompanied by a transfusion designed to replace lost blood. The transfusion was deemed necessary in order "to offer the best chance of recovery" in that "there was a very great chance that the patient would have little opportunity to recover without the blood."<sup>40</sup> The patient consented to the operation but refused the transfusion. In seeking an order to compel the transfusion, the superintendent of the hospital stated that the refusal represented the patient's calculated decision. The court noted:

The county argues that it is in violation of the Penal Law to take one's own life and that as a practical matter the patient's decision not to accept blood is just about the taking of his own life. The court [does not] agree...because it is always a question of judgment whether the medical decision is correct...[I]t is the individual who is the subject of a medical decision who has the final say..."

*Erickson* has been heralded by some as guaranteeing a competent patient the right to die under any and all circumstances. This, however, is a gross misreading of the *Erickson* decision. *Erickson* is not a "right to die" case; it is a case regarding the patient's right to determine the efficacy and appropriateness of a proposed protocol of treatment. A careful reading of *Erickson* leads to a recognition of three points which make this conclusion inescapable. The court explicitly denied that the patient was unquestionably *in extremis*. It was the *county's* contention that the patient's decision not to accept blood was tantamount to a decision to take his own life but "the court [does not] agree... because it is always a question of judgment whether the medical decision is correct'," <sup>42</sup> i.e., the court did not agree that refusal of blood represented an imminent danger of death. Although the odds for survival of the operation without a

transfusion were poor and transfusing the patient offered the “best chance” for recovery, the procedure might indeed have been successful without a transfusion. Thus refusal of a blood transfusion was not the functional equivalent of acceptance of death. Finally, and most significantly, every blood transfusion represents a trade-off between the risk inherent in loss of blood against the novel risks introduced by the transfusion itself, as well as the possibility that the transfusion might prove to be totally inefficacious. The balancing of these risks is also part of the “judgment whether the medical decision is correct.” Whenever such risks must be weighed, whenever such decisions must be made, “it is the individual who is the subject of a medical decision who has the final say.”<sup>43</sup> As one legal scholar has categorized this decision: “Whether these conclusions of the court were medically correct is irrelevant. They are the premises of the opinion.”<sup>44</sup> Since the patient was not in extremis and the proposed treatment was not regarded as absolutely necessary and, in addition, carried with it no guarantee of success, a question of “a right to die” does not arise.<sup>45</sup> The case was resolved on the basis of the firmly established principle that the patient has the right to make all necessary decisions regarding the efficacy, wisdom and choice of his own treatment. It is this principle—and only this principle—that was definitively enunciated in *Erickson*.

Another case frequently cited in this context is *In re Melideo*.<sup>46</sup> In *Melideo* the court refused to compel a life-saving transfusion necessitated by a uterine hemorrhage subsequent to a diagnostic dilation and curettage. The court stated,

[T]he patient is fully competent, is not pregnant, and has no children. Her refusal to submit to a blood transfusion even though it may be necessary to save her life, must be upheld.<sup>47</sup>

However, in *Melideo*, the patient sought to decline the transfusion on religious grounds. Thus, the issue was not simply that of a right to privacy, but of a First Amendment right of Free Exercise.

Neither the constitutionally protected right to privacy nor the right to Free Exercise as applied to religious practices is absolute. Even the privacies explicitly protected by the Constitution are not absolute. The public good permits searches and seizures with a warrant and, “if reasonable,” on probable cause even in the absence of a warrant. Self-incriminating testimony can be compelled if the witness is given immunity from prosecution.<sup>48</sup> However, a far more stringent standard is imposed for the setting aside of a Free Exercise privilege than for overcoming a right to privacy.



It is a well-established principle of constitutional law that not all rights are equally protected. Of the constitutionally protected rights, those guaranteed by the First Amendment occupy a “preferred position.”<sup>49</sup> Free exercise of religion can be compromised only in the face of a compelling State interest. Although there is as yet no definitive standard for justification of abrogating a right to privacy, it seems dear that the right to privacy is subservient to the realization of legitimate State interests that fall short of the compelling interest standard.<sup>50</sup> In a long series of decisions, courts have refused to order blood transfusions save in cases involving the State’s compelling interest as *parens patriae* in order to safeguard the welfare of children, to save the life of a mother of young children or of a pregnant woman. Accordingly, the Court in *Melideo* carefully predicated its decision upon the consideration that “where there is no compelling state interest which justifies overriding an adult patient’s decision not to receive blood transfusions *because of religious beliefs*, such transfusions should not be ordered.”<sup>51</sup> Absent such a belief and the concomitant assertion of a free exercise claim, the court would have had no hesitation in ordering the transfusion.<sup>52</sup>

There is, on the contrary, one New York case which affirms the State’s interest in preservation of life as overriding the patient’s constitutional right to privacy. *Von Holden v. Chapman* involved a prisoner, Mark Chapman, the convicted killer of John Lennon, who attempted to starve himself to death and invoked a constitutional right of privacy in support of his right to do so. The Court held that “the obligation of the State to protect the health and welfare of persons in its care and custody, its interest in the preservation of life and its interest in maintaining rational and orderly procedures in its institutions, are countervailing considerations of such importance as to outweigh any claimed right of appellant.”<sup>53</sup> It is clear that the Court regarded each of those considerations as independently sufficient, in and of itself, to affirm the State’s right to intervene. Thus, the court declared:

Even overlooking the fact that Chapman’s status as a prisoner severely delimits his constitutional privileges., it is self-evident that the right to privacy does not include the right to commit suicide. For, as has been repeatedly stated, “only personal rights that can be deemed ‘fundamental’ or ‘implicit in the concept of ordered liberty’-... are included in this guarantee of personal privacy.” To categorize a person’s self-destructive acts as entitled to that constitutional protection would be ludicrous.<sup>54</sup>

## Assertion of a State Interest

Although the State can derive no “benefit” from a non-sapient patient in a terminal condition, it nevertheless does maintain an interest in: (i) preserving respect for all human life lest disregard for the life of a non-sapient terminal patient engender debasement of all human life and (ii) permitting and encouraging health care professionals to provide life-sustaining care for all patients lest their professional and ethical sensitivities be dulled with resulting deleterious effects upon their ministrations to other patients entrusted to their care. These concerns, which apply so strongly in cases of attempted suicide on the part of competent adult patients, have even greater force when related to the terminally ill because of the latter’s vulnerability and helplessness. The concern for the interests of the physicians and the hospital were clearly recognized in *John F Kennedy Memorial Hospital v. Heston*.<sup>55</sup> Similarly, in *United States v. George*,<sup>56</sup> the Court declared that “the doctor’s conscience and professional oath must be respected” and accordingly refused to permit the withholding of a blood transfusion labeling such a course of action as “amounting to medical malpractice.”<sup>57</sup> Unfortunately, those concerns have not received the judicial attention they deserve. Given the prevailing climate of opinion, there is scant chance that those considerations will figure significantly in either ongoing judicial or legislative deliberations.<sup>58</sup> But it is crucial to the preservation of the moral sensitivities of society that those State interests which have received judicial recognition not be eroded or compromised. Specifically, society—through its judiciary and legislature—should not sacrifice its interest in preserving respect for human life by permitting untrammelled renunciation of medical treatment in circumstances in which the State’s right to intervene has been clearly defined, i.e., in circumstances in which the quality of life to be preserved meets the judicially defined threshold of State interest. This view of the State’s interest and obligation is best expressed in *John F. Kennedy Memorial Hospital v. Heston*.<sup>59</sup> In *Heston* the court held that:

If the State may interrupt one mode of self-destruction [suicide], it may with equal authority interfere with the others. It is arguably different when an individual, overtaken by illness, decides to let it run a fatal course. But unless the medical option itself is laden with the risk of death or of serious infirmity, the State’s interest in sustaining life in such circumstances is hardly distinguishable from its interest in the case of suicide.<sup>60</sup>

As stated by Justice Nolan in his dissenting opinion in *Brophy v. New England Sinai Hospital*,<sup>61</sup> “Suicide is direct self-destruction and is intrinsically evil. No set of circumstances can make it moral.”®

The selfsame concerns apply *a fortiori* to withholding of nutrition and hydration from even the terminally ill. Resolution of the debate regarding categorization of such measures as “treatment” or “care” is, in itself, specious insofar as the State interest is concerned. The crucial issue is that the debate itself and the moral shock elicited from many at the prospect of societal approval of withholding such measures demonstrates the inevitable effect of such approval upon society at large. Popular perception of food and water as needs more basic than medicine and their administration as inherently non-medical in nature is self-validating insofar as State interest is concerned.

In no less than four recent cases New York courts have wisely denied requests to withhold artificial nutrition. In *Vogel v. Forman*<sup>62</sup> Justice Alfred Robbins refused to allow a feeding tube to be removed from a patient who, although not terminally ill, was in a vegetative state following a stroke. Justice Robbins remarked that it is “inconceivable that the concept of death by starvation shall be embraced and established as a policy of this state” and declared that “our humane society has not yet embraced a concept of sympathetic euthanasia.”<sup>64</sup> In another case, *Delio v. Westchester County Medical Center*“ Justice Anthony Cerrato refused to approve removal of a feeding tube from a patient in a similar condition despite “clear and convincing” evidence that the patient would not have wanted his life prolonged under such circumstances. Justice Cerrato observed that to do so would only involve the courts in a yet unsanctioned broad scale policy of euthanasia.\* Yet another case, *In the Matter of Mary*

‘During the interval between submission of this material and its final printing, Justice Cerrato’s decision in *Delio* has been reversed by the Appellate Division, Second Department. *Matter of Delio*, N.Y.L.J., June 4, 1987 at 1, col.6. The Appellate Division has ruled that termination of artificial nutrition and hydration in accordance with the known wishes of the patient may be sanctioned “in cases involving a person existing in a chronic vegetative state with no hope of recovery.” This was rapidly followed by an even more permissive ruling by Justice Edward Conway in *Matter of Brooks*, N.Y.L.J., June 16, 1987 at 1 (Sup. Ct., Albany Co.). Despite the fact that the decision of the appeals court in *Delio* was limited to (1) withholding of artificial nutrition and (2) withholding of such nutrition only from a patient in a chronic vegetative state with no hope of recovery, Justice Conway felt “bound” by the *Delio* decision to permit a mentally competent nursing home patient not afflicted by a terminal illness to refuse food in order to starve herself to death. This writer remains convinced that the interest of the State in preventing suicide and euthanasia is sufficiently strong to warrant prohibition of withholding nutrition and hydration. These recent judicial decisions serve to underscore the need for appropriate legislation in this area

Chetta“ involved an 82 year old stroke victim who had been maintained on a nasogastric tube for 39 months and who was described as being in a persistent vegetative state. Despite “clear and convincing evidence” that the patient would have desired the removal of the feeding tube, Justice Becker, citing both *Delio* and *Vogel*, refused to sanction what he characterized as “death by starvation.” The most recent case, *Workman's Circle Home and Infirmary for the Aged v. Fink*<sup>67</sup>, involved a terminally ill patient who had been semi-comatose for two and a half years, and, at the time the decision was issued, also suffered from pneumonia. Despite a finding of clear and convincing evidence that the patient, when competent, had left instructions to terminate “any life-sustaining procedure when there is no hope of recovery,” Justice Tomkins refused to permit withholding of intravenous feeding or antibiotics.

Acceptance of the “right” to withdraw life-sustaining necessities from the terminally ill would constitute acceptance of a debasement of the value of human life as directly and as brutally as is inherent in condoning more conventional forms of suicide. Just as the court in *Hales* recognized that failure to criminalize suicide would result in debasement of the value of human life in the eyes of the public, so should our society recognize that, at the current juncture of human history, the inevitable effect of societal sanction for withholding of nutrition and hydration in the name of individual autonomy would be the erosion of the cardinal value of human life—a value recognized and cherished as the hallmark of every civilized society.

Every human life—without exception — is endowed with sufficient value to be worthy of the State’s protection. Failure to protect any human life is to deny the dignity of all human life. As stated by Justice O’Connor in *Brophy v. New England Sinai Hospital*:

Even in cases involving severe and enduring illness, disability and “helplessness,” society’s focus must be on life, not death, with dignity. By its very nature, every human life, without reference to its condition has a value that no one rightfully can deny or measure. Recognition of that truth is the cornerstone on which American law is built. Society’s acceptance of that fundamental principle explains why, from time immemorial, society through law has extended its protection to all, including, especially, its weakest and most vulnerable members.<sup>68</sup>

## Footnotes

1. T. HOBBS, LEVIATHAN, ch. 21.
2. N. ST. JOHN-STEVAS, LIFE, DEATH AND THE LAW: LAW AND CHRISTIAN MORALS IN ENGLAND AND THE UNITED STATES 233 (1961); Barry, *Suicide and the Law*, 5 MELB. U. L. REV. 1, 2 (1965).
3. H. BRACKTON, ON THE LAWS AND CUSTOMS OF ENGLAND 423 (S. Thorne trans. 1968).
4. Burgess-Jackson, *The Legal Status of Suicide in Early America: A Comparison with the English Experience*, 29 WAYNE L. REV. 57, 61, 64, 77-80 (1982).
5. Alabama, Oregon and South Carolina have each held suicide to be a crime. *See* Southern Life & Health Ins. Company v. Wynn, 29 Ala. App. 207, 194 So. 421 (1940); Wyckoff v. Mutual Life Ins. Co., 173 Or. 592, 147 P.2d 227 (1944); State v. Level, 34 S.C. 120, 13 S.E. 319 (1891).
6. *See* Royal Circle v. Achterrach, 204 111. 549, 68 N.E. 492 (1903); Wallace v. State, 232 Ind. 700, 116 N.E.2d 100 (1953); State v. Carney, 69 N.J.L. 478, 55 A. 44 (1903); *cf.* D.C. CODE ANN. §§ 22-103, -2401 (1981) ; Commonwealth v. Dennis, 105 Mass. 162 (1870).
7. ALASKA STAT. § 11.41.120 (1978); ARIZ. REV. STAT. ANN. § 13- 1103 (1978); ARK. STAT. ANN. § 41-1504 (1977); CAL. PENAL CODE § 401 (West 1970); COLO. REV. STAT. § 18-3-104 (1978); CONN. GEN. STAT. § 53a-56 (1981); DEL. CODE ANN. tit. 11, § 645 (1979); FLA. STAT. ANN. 782.08 (West 1976); HAWAII REV. STAT. § 707-702 (1976); KAN. STAT. ANN. § 21-3406 (1981); Commonwealth v. Hicks, 118 Ky. 637, 82 S.W. 265 (1904); ME. REV. STAT. ANN. tit. 17-A, § 204 (1982) ; Commonwealth v. Mink, 123 Mass. 422 (1877); MINN. STAT. ANN. § 609.215 (West 1964); MISS. CODE ANN. § 979-3-49 (1972); Mo. Ann. Stat. § 565.021 (Vernon 1979); Mont. Code Ann. § 45-5-105 (1981) ; NEB. REV. STAT. § 28-307 (1979); N.J. STAT. ANN. 2C:11-6 (West 1981); N.M. STAT. ANN. § 30-2-4 (1978); N.Y. PENAL LAW § 120.30 (McKinney 1975); Blackburn v. State, 23 Ohio St. 146 (1872); Okla. STAT. ANN. tit. 21, §§ 813-818 (West 1958 & Supp. 1981-1982); OR. REV. STAT. § 163.125 (1981); 18 PA. CONS. STAT. ANN. § 2505 (Purdon 1973); PR. LAWS ANN. tit. 33, § 1385 (1969); State v. Jones, 86 S.C. 17, 67 S.E. 160 (1910); S.D. CODIFIED LAWS ANN. § 22-16-37 (1979); Turner v. State, 119 Tenn. 663, 108 S.W. 1139 (1908); TEX. PENAL CODE ANN. § 22.08 (Vernon 1974); WASH. REV. CODE ANN. § 9A.36.060 (1977); WIS. STAT. ANN. § 940.12 (West 1982).

8. 265 Pa. Super. 570, 402 A.2d 692 (1979), *revd on other grounds*, 498 Pa. 639, 450 A.2d 638, (1982). When there exists a legal duty to care for or to protect another, any act of omission results in criminal liability when failure to act proximately causes death and the omission occurs with knowledge of the consequences or through negligence. *See* W. LaFAVE & A. SCOTT, HANDBOOK OF CRIMINAL LAW 182-91 (1st ed. 1972); J. TURNER, RUSSELL ON CRIME 402 (12th ed. 1964); G. WILLIAMS, CRIMINAL LAW: THE GENERAL PART, (2d. ed. 1978); Frankel, *Criminal Omissions: A Legal Microcosm*, II WAYNE L. REV. 267 (1965); Glazebrook, *Criminal Omissions: The Duty Requirement in Offenses Against the Person*, 76 L.Q. REV. 386 (1960); Hughes, *Criminal Omissions*, 67 YALE L.J. 590 (1958); Perkins, *Negative Acts in Criminal Law*, 22 IOWA L. REV. 659 (1937); Rudolph, *Duty to Act: A Proposed Rule*, 44 NEB. L. REV. 499 (1965).
9. *See* *In re Caulk*, 125 N.H. 226, 228, 231-232, 480 A.2d 93, 94, 96-97 (1984) (refused to permit suicide by starvation).
10. 211 N.Y. 125, 105 N.E. 92 (1914).
11. *Id.* at 129-30, 105 N.E. at 93.
12. J.S. MILL, ON LIBERTY 125 (1956).
13. *See* Byrn, *Compulsory Life Saving Treatment for the Competent Adult*, 44 FORDHAM L. REV. 1, 20 (1975). Cf. *Furman v. Georgia*, 408 U.S. 228, 290 (1972) (Brennan, J. concurring) (“An executed person has indeed ‘lost the right to have rights’”). At the other end of life, the contradiction has been noted in actions brought by a child for “wrongful birth”. *See* *Gleitman v. Cosgrove*, 49 N.J. 22, 227 A.2d 689 (1967); *Williams v. State*, 18 N.Y.2d 481, 223 N.E.2d 343, 276 N.Y.S.2d 885 (1966).
14. As stated in *Barbier v. Connolly*, 113 U.S. 27, 31 (1884), “But neither the [14th] Amendment—broad and comprehensive as it is—nor any other amendment was designed to interfere with the power of the state, sometimes termed police power, to prescribe regulations to promote the health, peace, morals, education, and good order of the people.” *See also*, *Lochner v. New York* 198 U.S. 45 (1905); *Mugler v. Kansas*, 123 U.S. 623, (1887); *Re Kemmler*, 136 U.S. 436 (1890); *Crowley v. Christensen*, 137 U.S. 86, (1890); *Re Converse*, 137 U.S. 624 (1891).
15. *Hales v. Petit*, 1 Plowden 253, 75 Eng. Rep. 387 (1562).
16. 75 Eng. Rep. at 400.
17. 4 BLACKSTONE’S COMMENTARIES 189.

18. WRITINGS OF THOMAS JEFFERSON 310 (Lipscomb & Bergh eds. 1903).
19. Commonwealth v. Mink, 123 Mass. 422, 425 (1877).
20. 56 Misc. 2d 318, 288 N.Y.S.2d 931 (1968).
21. 76 N.J. Super. 493, 185 A.2d 21 (1963).
22. *Id.* at 511-12, 185 A.2d at 31. Similarly, in *Bisenius v. Karns*, 42 Wise.2d 42, 165 N.W.2d 377, *appeal dismissed*, 395 U.S. 709 (1969) a Wisconsin court declared that if it is deemed fatal to a statute that it seeks only to protect a person against his own actions, many statutes would be suspect, including laws requiring hunters to wear bright jackets, prohibiting riders on motor-driven cycles from attaching same to any other vehicle on the highway, requiring lifeboats to be equipped with life preservers, prohibiting aerial performances without a net, requiring water skiers to wear life preservers, requiring tunnel workers to wear protective helmets and other industrial employees to wear protective goggles.
23. 75 Eng. Rep. at 400.
24. In a study of what has been labeled the Werther Syndrome—the tendency of people to imitate a publicized suicide—Dr. David Phillips, a sociologist at the University of California at San Diego, has found that a significant rise in suicides occurs after every publicized case of suicide. A nationally publicized suicide, he found, increases the suicide rate by approximately 2% and by 7% among teenagers, who are highly imitative. According to Dr. Phillips, “Hearing about a suicide seems to make those who are vulnerable feel they have permission to do it.” See also Alvarez, *THE SAVAGE GOD* 58, 109 (1970). It is of topical interest to note that a recent study by Dr. David Shaffer, a professor of child psychiatry at Columbia University, has demonstrated that the effect of media reports concerning teenage suicide is a significant increase in both successful suicide and suicide attempts among young people. Professor Shaffer notes that there exists considerable imitation or “contagion” with regard to the phenomenon of youth suicide. See *The New York Times*, March 12, 1987, at B6, col. 4. That item appeared in conjunction with news reports of a suicide pact in which four Bergenfield, N.J. teenagers died. Less than a week later, on March 18, 1987, the *Times* reported the rescue by police of two other teenagers who had almost succeeded in committing suicide in the same place and in an identical manner. See *The New York Times*, March 18, 1987, at A1, col. 2. Another similar incident is reported in *The New York Times*, March 14, 1987, at 30, col. 2.

25. Roe v. Wade, 410 U.S. 113 (1973).
26. Union Pacific Rwy. v. Botsford, 141 U.S. 250 (1891).
27. Terry v. Ohio, 392 U.S. 1 (1968).
28. Jacobson v. Massachusetts, 197 U.S. 11 (1905).
29. Schmerber v. California, 384 U.S. 757 (1966).
30. Von Holden v. Chapman, 87 A.D.2d 66, 68, 450 N.Y.S.2d 623, 625 (1982).
31. Penney v. Municipal Ct, 312 F. Supp. 938 (D.N.J. 1970).
32. 331 F.2d 1008, *cert, denied*, 377 U.S. 978 (1964).
33. 331 F.2d at 1008-09.
34. 70 N.J. 10, 355 A.2d 647 (1976).
35. 355 A.2d at 664.
36. 52 N.Y.2d 363, 420 N.E.2d 64, 438 N.Y.S.2d 266 (1981).
37. *Id.* at 377-78 n.6, 420 N.E.2d at 71 n.6, 438 N.Y.S.2d at 273 n.6.
38. 44 Misc. 2d 27, 252 N.Y.S.2d 705 (1962).
39. *Id.* at 26, 252 N.Y.S. 2d at 706.
40. *Id.*
41. *Id.*
42. *Id.* (emphasis added).
43. *Id.*
44. Byrne, *supra* note 13, at 3.
45. *Id.* at 3 n.12.
46. 86 Misc.2d 974, 390 N.Y.S.2d 523 (1976).
47. *Id.* at 975, 390 N.Y.S.2d at 524.
48. New York Times v. United States, 403 U.S. 717, 727-48 (1971) (White, Stewart and Marshall, J.J., concurring).
49. See Marsh v. Alabama, 326 U.S. 501, 509, (1946) (“When we balance the Constitutional rights of owners of property against those of the people to enjoy freedom of press and religion, we remain mindful of the fact that the latter occupy a preferred position.”).



Although rights secured by the First Amendment are for the first time accorded a preferred position vis-a-vis other rights in the Marsh decision, the phrase "preferred position" has long been used to describe the freedom specified by the First Amendment. The phrase was first used in the dissent of Chief Justice Stone in *Jones v. Opelika*, 316 U.S. 584, 600, 608, (1942). It reappears in *Murdock v. Pennsylvania*, 319 U.S. 105, 115 (1943); *Prince v. Massachusetts*, 321 U.S. 158, 164, (1944); *Marsh v. Alabama*, 326 U.S. at 509; *Saia v. New York*, 334 U.S. 558, 562 (1948); *Kovacs v. Cooper*, 336 U.S. 77, 88 (1949). Cf. *Kovacs*, 336 U.S. at 93 (Frankfurter, J., concurring) and *id.* at 106 (Rutledge, J., dissenting).

50. See, e.g., *Wyman v. James*, 400 U.S. 309 (1971) (home visit by caseworker in conjunction with dispensation of AFDC program is not an unwarranted invasion of personal privacy).

86 Misc.2d at 975, 390 N.Y.S. 2d at 524 (emphasis added). This statement should not be construed as conferring legal sanction upon all forms of suicide when based upon an assertion of a Free Exercise claim. The Supreme Court in *Reynolds v. U.S.*, 98 U.S. 145, 166 (1878), in an early formulation of the notion of a compelling state interest, queried rhetorically, "[I]f a wife religiously believed it was her duty to burn herself upon the funeral pyre of her dead husband, would it be beyond the power of the civil government to prevent her carrying her belief into practice?" Presumably, the *Melideo* court regarded benign neglect of not ordering a blood transfusion as below the threshold that would compromise a compelling state interest, perhaps because of the passive nature by which the life would be lost, perhaps because the patient might have died in any event either because of blood incompatibility or because of the underlying medical problem, possibly because, in the court's estimation, omission of a procedure of such nature would not be perceived as a blatant denigration of the value of life, or possibly because of a combination of these considerations. But see *Morrison v. State*, 252 S.W.2d 97, 103 (Mo. App. 1952), which entertains the possibility that a "religious zealot" may have the right to fast until death. Nevertheless other courts have ruled that the State may prohibit the handling of poisonous snakes in religious ceremonies even though the danger is limited to only the willing participants. *Hull v. State*, 38 Ala. App. 404, 88 So. 2d 880, cert. denied, 38 Ala. 697, 88 So. 2d 887 (1956); *Lawson v. Commonwealth*, 291 Ky. 437, 164 S.W.2d 972 (1942). Similarly, in *People v. Woody*, 61 Cal. 2d 716, P.2d 813, 40 Cal. Rptr. 69 (1964), although a state statute prohibiting the use of peyote was held to be unconstitutional as applied to members of a religious sect which used the drug in its ceremonies, the court implied that had the State shown the substance to be injurious to the morals and health of the practitioners,

curtailment of the religious practice would have been justified. In *Quinlan* the court rejected the plaintiffs argument that the right to die is a religious belief protected by the Free Exercise Clause by drawing the familiar distinction between religious belief and religious practice. 355 A.2d at 647.

51. Nor does *People v. Robbins*, 83 A.D.2d 271, 443 N.Y.S.2d 1016 (1981), support the proposition that a patient is always free to refuse life-saving intervention. In *Robbins*, the court ruled that a husband was not guilty of criminally negligent homicide in not summoning medical attention for his wife who declined such assistance. The court did indeed cite *Storar* in such a context without acknowledgment of the fact that *Storar* involved a terminally ill patient but only in support of its holding that “[I]t would be an unwarranted extension of the spousal duty of care to impose criminal liability for failure to summon medical aid for a competent adult spouse who had made a rational decision to eschew medical assistance.” Although not emphasized in the court’s holding, Mrs. Robbins declined treatment on religious grounds and, presumably, the court would have had little difficulty in affirming her right to do so on Free Exercise grounds. Nevertheless, even were the patient not capable of asserting a right against which State interest would not prevail, refusal of treatment is certainly recognized in *Robbins* as extinguishing the spousal duty of care. That holding is entirely cogent and does not mitigate the State’s right to compel treatment. The State’s interest and right in pre-serving life does not generate a concomitant duty devolving upon the spouse since spousal duty is a duty to the spouse rather than to the State.

52. 87 A.D. 2d at 66-67. An identical ruling was issued by a New Hampshire court in *In re Caulk*, 125 N.H. 225, 480 A.2d 93 (1984), in a case involving similar facts. In *Caulk* a prisoner was not allowed to starve himself to death because the State’s interest in preservation of life was held to take precedence over the individual’s constitutional rights.

53. *Id.* at 68 (citations omitted).

54. 58 N.J. 576, 279 A.2d 670 (1971).

55. 239 F. Supp. 752 (D.Conn. 1965).

56. *Id.* at 754.

57. *But see* Commissioner of Corrections v. Myer, 379 Mass. 255, 399 N.E.2d 452 (1979) (preservation of the ethical integrity of the medical profession grounds for countermanding refusal of life-saving treatment).
58. 58 N.J. 576, 279 A.2d 670 (1971),
59. *Id.* at 581-82, 279 A.2d at 673.
60. 398 Mass. 417, 497 N.E.2d 626 (1986).
61. 497 N.E.2d at 640.
62. 512 N.Y.S.2d 622 (Sup. Ct., Nassau Co. 1986).
63. *Id.* at 624.
64. 134 Misc.2d 206, 510 N.Y.S.2d 415 (1986).
65. No. 1086-87 (Sup. Ct., Nassau Co. May 1, 1987).
66. 512 N.Y.S.2d 622 (Sup. Ct., Bronx Co. 1987).
67. 497 N.E.2d at 646.



## **Part Two**

### **The Health Care Proxy: Recommendations and Proposed Legislation**



## Introduction

In recent years, there has been a ground swell of support for allowing individuals greater control over medical technologies used at the end of life. Often described as the “right to die” or the right to “death with dignity,” it is a right long-recognized in our legal and medical traditions—the right of informed consent and its corollary, the right to refuse treatment. Although well-established in theory, this fundamental right is often relinquished in practice because the patient lacks the capacity to exercise the right at the critical time decisions must be made.

Two legal instruments have been created to assure that a person’s health care choices are respected after the person has lost decision-making capacity. Those vehicles are “living wills,” specifying health care instructions, and “durable powers of attorney,” or other documents appointing a health care agent or surrogate to make decisions on a person’s behalf.

In New York State, and elsewhere, the need for policies that protect the individual’s participation in decisions about the dying process has been widely recognized. Public opinion polls have shown steady and overwhelming support for allowing persons the right to forego treatment at the end of life.<sup>1</sup> At present, over 80,000 people in New York State have signed living wills to exercise this right, even in the absence of legislative recognition of the documents.<sup>2</sup>

The Task Force concluded that a mechanism for decisions about more routine treatment for persons without decisional capacity is also urgently needed. Without policies to enhance the decision-making process for adults without capacity, highly effective, beneficial treatment is delayed for some patients, while others are maintained on life-support systems, perhaps indefinitely, in violation of their strongly held beliefs and wishes.

The Task Force studied these issues and the alternatives for responsive public policy. Part Two of this Report describes the Task Force’s recommendations for legislation permitting the appointment of a health care agent and the ethical, legal and medical considerations underlying those recommendations. The legislative proposal appears as Appendix A to this Report.

## Footnotes

1. See discussion, pp. 5-6.
2. *Saunders v. State*, 129 Misc. 2d 45, 492 N.Y.S.2d 510 (Sup. Ct., Nassau Co. 1985).



## **IV. Making Decisions in Advance— The Living Will and Health Care Proxy**

Two kinds of instruments, referred to as “advance directives,” have been developed to enable persons to retain some control over health care decisions after they have lost the capacity to participate directly in the decision-making process: (i) written instructions about treatment, and (ii) the appointment of a person, often called an “agent” or “surrogate,” with the authority to make health care decisions on the person’s behalf.

### **Living Wills**

A living will is a document that contains a person’s instructions about treatment, to be followed in the event the person becomes incapable of making treatment decisions directly.<sup>1</sup> While living wills may specify a person’s preferences about a range of health care matters, they usually relate solely to wishes about life-sustaining treatment.

When expressed in a living will or other form, the written wishes of a person no longer competent may provide valuable guidance to family members and health care providers. A living will instructs the family about a person’s wishes and eases the burden of making difficult decisions. It may also constitute the informed consent needed by health care providers and protect them from civil and criminal liability when they terminate life-support systems in accordance with a patient’s wishes.<sup>2</sup>

The guidance offered by living wills, however, does not necessarily remove all doubts about a person’s wishes.<sup>3</sup> By their very nature, living wills cannot embody contemporaneous decisions; they are written in advance of the time when treatment decisions must be made. Thus, they do not represent an informed choice among alternatives in the immediate circumstances. Moreover, the language of living wills is often general, leaving it unclear how the patient’s wishes should be applied to a particular decision. Many living wills express a decision to forego “extraordinary” or “heroic” measures.<sup>4</sup> Such terms are relative; their interpretation may be entirely subjective or dependent upon an evaluation of the patient’s condition in light of the proposed treatment. For example, cardiopulmonary resuscitation may not be “heroic” for an otherwise healthy person who suffers an arrest during surgery. In contrast, even the provision of antibiotics might be considered “heroic” for a terminally ill person at the end stage of the dying process.

Initially developed to provide guidance to health care providers and family members, living wills increasingly have been relied on as legal documents to establish the rights of patients and define the legal obligations of health care providers.<sup>5</sup> Two basic questions about the legal significance of the documents have arisen: (i) can health care providers be liable for terminating treatment in accordance with the wishes expressed in a living will, and (ii) are health care providers obligated to follow the preferences stated?

In response to this uncertainty, many states have enacted legislation to clarify the circumstances under which living wills are valid and to determine the rights and obligations afforded patients and health care providers under the documents. California was the first state to pass such legislation in 1976.<sup>6</sup> As of March 1987, 37 other states and the District of Columbia had passed laws referred to as “living will” or “natural death” legislation.<sup>7</sup>

No such legislation has been enacted in New York, although related bills have been introduced in the Legislature since 1977.<sup>8</sup> Judicial decisions in New York, however, provide legal support for the use of and reliance upon living wills. As discussed previously, the Court of Appeals, in *Eichner v. Dillon*, held that life-sustaining treatment could be withdrawn based on “clear and convincing evidence” that the withdrawal of treatment was consistent with wishes expressed by the patient, prior to the patient’s loss of decisional capacity.<sup>9</sup> In the *Eichner* case, those wishes had been expressed orally several years earlier.

A written statement such as a living will would provide even more reliable evidence of the person’s wishes. Nonetheless, following the *Eichner* case, the form and content of wishes that would constitute the “clear and convincing” evidence required in *Eichner* remained unclear.

In 1985, a lower court in New York addressed this question in *Saunders v. State of New York*.<sup>10</sup> In that case, a competent 70 year- old woman with a progressive terminal illness sought a court order requiring health care professionals to honor her living will in the event she subsequently lost decision-making capacity. The court held that if Ms. Saunders later became incapacitated the wishes expressed in the living will would serve as informed medical consent for the withholding of life-sustaining treatment. The court also recognized that such consent would protect health care providers from liability if they followed those wishes in good faith.<sup>11</sup>

When the Task Force began to examine this issue, it was clear that uncertainty about living wills remained and that the response of health care providers in New York State to living wills diverged widely. The Task Force distributed a questionnaire to hospitals and nursing homes in the State to assess the range and patterns of responses to living wills.

The questionnaires were sent to all members of the New York State Hospital Association, which comprise approximately 89% of the 268 hospitals in the State. A similar questionnaire was sent to 622 nursing homes, reaching virtually all skilled nursing facilities in the State. One hundred thirty-nine (58%) of the hospitals and 196 of the nursing homes (32%) replied.<sup>12</sup>

The questionnaire asked how hospitals and nursing homes respond to living wills generally and the specific conditions which must be met before a living will would be honored. Sixteen percent of the hospitals and 27% of the nursing homes responded that they would honor living wills. Another 45% of the hospitals and 27% of the nursing homes said that they would honor them under some circumstances. Twenty-nine percent of the hospitals and 17% of the nursing homes answered that they would not honor living wills; 10% of the hospitals and 29% of the nursing homes indicated that they did not have a policy on living wills.<sup>13</sup>

Although these figures suggest that a significant number of hospitals and nursing homes will abide by the wishes expressed in a living will, further inquiry revealed that those facilities that accept living wills do so only under limited circumstances. Of the facilities which indicated that they honor living wills under some circumstances, 69% of the hospitals and 61% of the nursing homes do not honor wishes expressed in a living will unless the patient affirms those wishes during hospitalization. Sixty-four percent of those hospitals and 68% of the nursing homes do not comply with a living will if the attending physician objects, while 57% of the hospitals and 53% of the nursing homes do not proceed in the face of opposition by the patient's family. Finally, 34% of the hospitals and 38% of the nursing homes do not honor wishes expressed in a living will unless those wishes name the specific treatments to be withheld.<sup>14</sup>

The questionnaire thus reveals that, despite clear legal support, many hospitals and nursing homes are reluctant to honor the wishes expressed in a living will, unless a panoply of other conditions are met. Those conditions, especially the requirement that patients affirm the wishes expressed in a living will during hospitalization, undermine the usefulness of the documents for patients.

## **Appointment of a Health Care Agent**

Individuals may also seek to control decisions about health care after they have lost capacity by appointing another person to act as their agent or surrogate. The appointment of an agent or surrogate enables someone chosen by the patient to participate in the decision-making process in the patient's place. The agent is fully informed by the patient's physician, has access to all relevant information, and makes a decision on the patient's behalf.<sup>15</sup>

Appointment of a health care agent responds to the two essential questions facing family members and health care providers when a patient lacks decision-making capacity: who decides and on what basis should the decision be made? By responding directly to the first question, the appointment of an agent avoids uncertainty and conflict about which family member or other person close to the patient should speak for the patient.

Individuals who designate an agent have the opportunity to inform the agent, in writing or orally, about their treatment preferences. Written instructions can be included in the document appointing the agent, in a living will, or in some other form. The value of such instructions is enhanced since the agent is available to ensure that those decisions are carried out or to interpret them in light of unanticipated circumstances.

Appointment of a health care agent avoids the difficulty, inherent in the use of living wills, of trying to anticipate future medical circumstances and make treatment choices at a time which may be far removed from the actual events. Guided by the patient's general preferences and specific directions, an agent makes a contemporaneous decision, based on all available information about the patient's prognosis, treatment alternatives and anticipated outcomes.

Finally, appointment of a health care agent provides a vehicle for decision-making about a wide range of medical circumstances. An agent's authority is usually not limited to life-sustaining treatment. In fact, the powers delegated to an agent may also include the authority to: provide or withhold consent to medical treatment; employ and discharge medical personnel; have access to and disclose medical information; and authorize the expenditure of the patient's funds for medical treatment.

Since an agent's authority is so far-reaching, measures must be taken to ensure that the delegation is fully informed and voluntary. Adequate safeguards must be developed to protect persons of diminished

capacity, such as those' among the institutionalized elderly or mentally disabled, who may not completely understand the scope of the powers delegated and the significance of the document for their lives and welfare.

## **Legislation on Health Care Agents**

### **Other States**

The appointment of an agent is a long-established practice in financial and business transactions. In that context, the appointment is made with a document called a power of attorney. By signing a power of attorney, an individual ordinarily referred to as the "principal" may delegate authority to an agent to oversee a broad range of business matters or to conduct particular transactions, such as the purchase or sale of a home.

All fifty states have statutes that permit the use of a power of attorney to delegate authority for financial matters.<sup>17</sup> Under a special "durable" power of attorney, the agent's authority may continue, even when the principal loses capacity to act for himself or herself.

Most durable power of attorney statutes do not expressly refer to health care decisions. While many legal commentators believe that these statutes implicitly permit the delegation of authority to make health care decisions, uncertainty remains.<sup>17</sup>

Consequently, sixteen states have enacted laws expressly authorizing the appointment of an agent for health care decisions.<sup>18</sup> These statutes have been passed in three different forms: (i) a separate statute creating a durable power of attorney for health care; (ii) amendment to an existing durable power statute, extending the statute to include health care; and (iii) inclusion of provisions in living will legislation to permit appointment of a health care agent.<sup>19</sup>

### **New York Law on Appointing a Health Care Agent**

New York, like all other states, has a durable power of attorney statute.<sup>20</sup> The statute was designed to allow delegation of authority for financial matters and does not refer to health care decisions. In 1984, the New York Attorney General was asked whether the power of attorney could be extended to authorize decisions about health care. In an opinion that has established the present legal framework for the issue, the Attorney General stated that, "a durable power is an uncertain vehicle for delegation of authority generally for an agent to make health care decisions on behalf of an incompetent person."<sup>21</sup> The Attorney General rested his opinion on the fact that the durable power statute addresses only financial and estate matters.<sup>22</sup>

The Attorney General acknowledged that the power could serve a more limited purpose for health care decisions: it could be used to authorize another person to communicate specific decisions made by the principal.<sup>23</sup> For example, if the principal specified in writing a decision to decline artificial respiration if he or she ever became permanently

unconscious, the agent could consent to the withdrawal of the respirator in those circumstances. This limitation, however, makes the power equivalent to a living will and eliminates its real value: appointment of an agent with authority to make decisions in the myriad of circumstances that cannot be anticipated. Hence, the durable power of attorney is not currently considered a valid means to delegate general authority for medical decisions in New York, although it can be used to delegate responsibility to carry out particular decisions anticipated by the patient.

In its questionnaire to health care facilities in the State, the Task Force asked how facilities respond to a durable power of attorney. In response to the question, "Does your facility honor a durable power of attorney for health care?" 39% of the hospitals and 41% of the nursing homes responded affirmatively; 46% of the hospitals and 52% of the nursing homes responded negatively; 16% of the hospitals and 6% of the nursing homes said that they did not have a policy on durable powers.<sup>24</sup>

Given the legal uncertainty about using a power of attorney for health care matters, a surprisingly high percentage of health care facilities honor the documents. Nonetheless, fewer than half the facilities in the State honor the documents and uncertainty persists about their legal status.

### **Task Force Recommendations— Legislation on the Health Care Proxy**

Rapid advances in medical technology continually change the context and nature of treatment choices. It is therefore increasingly difficult for individuals to anticipate and make treatment decisions months or years prior to the onset of serious and often sudden illness. By choosing an agent committed to honoring their preferences and educating the agent about those preferences, individuals can effectively extend their self-determination to the full range of medical circumstances which may arise.

The Task Force believes that appointment of an agent is the best vehicle to protect a person's rights and interests following the loss of decision-making capacity. Designation of an agent extends the patient's participation in health care decisions and enhances the outcome for the patient by providing a decision-making process that is flexible and responsive to actual circumstances. It also covers a wider range of health care decisions than living wills, which address only decisions about life-sustaining treatment.

Given the limited legal support in New York for using the durable power for treatment decisions, legislation is needed to provide an enforceable right to appoint a health care agent. By permitting an agent's appointment for all treatment decisions, including decisions about life-sustaining measures, the legislation would fill a critical gap in the current legal framework for health care decisions in New York State. It would also provide individuals with a powerful new mechanism to ensure that their wishes are respected even after they have lost the ability to express those wishes.

The Task Force therefore proposes legislation that would empower adults to appoint a health care agent by using a document called a "health care proxy." The Task Force chose

the term “health care proxy” rather than “durable power of attorney” to highlight the fact that the proxy relates to health care, not financial matters, and is governed by its own set of rules.

While the Task Force recommends health care proxy legislation, it recognizes that a range of mechanisms should be available to guide decisions about life-sustaining and other treatments for persons without capacity. Such mechanisms should include living wills, since some people may prefer not to delegate authority for health care decisions to another person, or may have no one to appoint.

The Task Force believes that, for purposes of legislative action, living wills should be addressed in the broader context of a decision-making process for persons without capacity who have not appointed a health care agent. Written instructions are one of several ways in which a person’s preferences may be determined, along a spectrum which includes oral statements and inferences from general values and life goals. The Task Force is now examining legislation in other states that combines recognition of living wills with a process for surrogate decision-making when a living will is not available.<sup>23</sup>

The Task Force has concluded that legislation on living wills, unless it is part of a comprehensive scheme for decision-making for all patients without capacity, might actually diminish, rather than enhance, patients’ rights to refuse treatment. Current New York law provides strong support for reliance on living wills.<sup>26</sup> It also permits the withdrawal or withholding of treatment based on other evidence of the patient’s wishes. That evidence may include oral statements made by the patient.<sup>27</sup>

Living will legislation grants legal sanction only to written instructions about treatment. It may therefore result in the exclusion of other ways in which treatment decisions are expressed and honored.<sup>28</sup> For example, if living wills alone are given legal recognition, health care providers may be unwilling to honor wishes that patients expressed orally prior to the loss of decision-making capacity.

Although living wills might become more widely used following enactment of state legislation, they are likely to remain a tool for an informed minority of the population.<sup>29</sup> For most people, failure to prepare a living will might render their explicit oral statements about medical treatment ineffective.

In addition, many of the policies set forth in existing living will statutes must be examined in light of the developing body of law concerning the constitutional right to refuse treatment. While the statutes seek to extend the person’s control over decisions at the end of life, many circumscribe that right far more than existing court decisions.<sup>30</sup> Moreover, seeking to prevent abuses, some of the laws actually make it more difficult for persons to have their wishes respected by imposing cumbersome requirements before a living will is considered valid.<sup>31</sup>

The Task Force recognizes that there is strong public support for living will legislation. Nonetheless, it believes that this support has emerged because the public identifies the

opportunity to exercise control over decisions at the end of life solely with such legislation. The notion of appointing an agent, combined with the opportunity to provide treatment instructions, has received less public attention and consideration. The Task Force believes that its legislative proposal responds to the public's underlying concern. It will allow people to specify their decisions about treatment in a manner that encompasses a broader range of medical circumstances and provides a better decision-making process than reliance on a living will.

The appointment of an agent, however, is not an option for those who have no close family member or friend they wish to appoint. Many elderly people in long-term care and psychiatric facilities face this situation since they have outlived or been abandoned by others once close to them. Passage of legislation on the health care proxy would not leave these persons without a means to extend their control over treatment decisions. Current New York law protects the right of each person to have treatment decisions honored if those decisions are expressed in a living will or another form. Completion of a living will in consultation with health care providers would constitute the kind of clear evidence required by the Court in *Eichner* and recognized as informed consent in *Saunders*.

Although health care providers are reluctant to honor living wills, this reluctance can be addressed by public education. These educational efforts should be targeted to inform professionals and patients in long-term care and other medical facilities about existing legal support for living wills. Moreover, long-term care and other facilities should be encouraged to develop procedures to promote creation of and reliance on the documents.

## Footnotes

1. See generally, Concern for Dying, *The Living Will and Other Advance Directives: A Legal*



*Guide to Medical Treatment Decisions* (New York: 1986); Society for the Right to Die, *Handbook of 1985 Living Will Laws* (New York: 1986).

2. *Saunders v. State*, 129 Misc. 2d 45, 492 N.Y.S.2d 510, 513 (Sup. Ct., Nassau Co. 1985).

3. A recent case, *Matter of Essner*, No. 21748/86 (Sup. Ct., Bronx Co. Dec. 17, 1986) illustrates this problem. See discussion, p. 27. For other descriptions of the difficulty of applying living wills in clinical circumstances, see Sisela Bok, "Personal Directions for Care at the End of Life," *NEJM*, Vol. 295, No. 7, Aug. 12, 1976, pp. 367-369; Stuart Eisendrath and Albert Jonsen, "The Living Will: Help or Hindrance?" *JAMA*, Vol. 249, April 15, 1983, p. 2054; David Hilfiker, "Allowing the Debilitated to Die," *NEJM*, Vol. 308, No. 12, March 24, 1983, pp. 716-19.

4. For example, a living will form widely distributed by Concern for Dying states:

If at such a time the situation should arise in which there is no reasonable expectation of my recovery from extreme physical or mental disability, I direct that I be allowed to die and not be kept alive by medications, artificial means, or "heroic measures."

Concern for Dying now recommends making a living will as specific as possible. Concern for Dying, p. 29.

5. President's Commission, *Deciding to Forego Life-Sustaining Treatment*, p. 139.

6. California Natural Death Act, Cal. Health & Safety Code §§ 7185 — 7195 (Supp. 1987).

7. The following 38 states and the District of Columbia have living will statutes: Alabama, Alaska, Arizona, Arkansas, California, Colorado, Connecticut, Delaware, Florida, Georgia, Hawaii, Idaho, Illinois, Indiana, Iowa, Kansas, Louisiana, Maine, Maryland, Mississippi, Missouri, Montana, Nevada, New Hampshire, New Mexico, North Carolina, Oklahoma, Oregon, South Carolina, Tennessee, Texas, Utah, Vermont, Virginia, Washington, West Virginia, Wisconsin, Wyoming. The 12 states that do not have living will statutes are: Kentucky, Massachusetts, Michigan, Minnesota, Nebraska, New Jersey, New York, North Dakota, Ohio, Pennsylvania, Rhode Island and South Dakota. For the text of most living will laws, see Society for the Right to Die, *Handbook 1985* and Society for the Right to Die, *Handbook of Living Will Laws 1981-1984* (New York: 1984).

8. A. 2383 (A. HevesyX1977). See generally, "To Die or Not to Die: The New York Legislature Ponders a Natural Death Act," 13 *Fordham Urb. L.J.* 639 (1985). Five living will bills were introduced during the 1986-87 legislative session: S. 859 (S. Jenkins, Jan. 22, 1987), A. 2016 (A. Koppell, Jan. 28, 1987), A. 3221 (A. Kramer, et al., Feb. 17, 1987), S. 4525 (S. Goodhue et al., March 31, 1987) and A. 8182 (Committee on Rules, June 10, 1987). The New York Legislature has just enacted a bill, proposed by the Task Force on Life and the Law, governing the issuance of do-not-resuscitate orders. S. 413-A, A. 678-A (S. Lombardi, A. Tallon et al., Jan. 7, 1987) The bill will, among other matters, authorize adults to make advance directives regarding the provision or withholding of cardiopulmonary resuscitation. See generally, Task Force, *Do Not Resuscitate Orders: The Proposed Legislation and Report of the New York State Task Force on Life and the Law* (New York: 1986).

9. See discussion, pp. 26-27.

10. *Saunders a State*, 129 Misc. 2d 45, 492 N.Y.S.2d 510, 513 (Sup. Ct., Nassau Co. 1985).
11. *Id.*, 492 N.Y.S.2d at 517.
12. See "Policies on Life-Sustaining Treatment: Survey of New York Hospitals and Nursing Homes," Appendix B to this Report, Table A.
13. *Id.*, Table E, pp. 174-75.
14. *Id.*, Table F, p. 176.
15. For discussion of the advantages of appointing a health care agent, see Bok, pp. 368-69; Francis Collin, Jr., John Lombard, Jr., Albert Moses and Harley Spitler, *Drafting the Durable Power of Attorney* (Lexington, SC: R.P.W. Publishing Corp. 1984), pp. 24-38; A. Edward Doudera, Jr., "Developing Issues in Medical Decision-Making: The Durable Power of Attorney and Institutional Ethics Committees," *Primary Care*, Vol. 13, No. 2, pp. 315-26; Dale Moore, "The Durable Power of Attorney as an Alternative to the Improper Use of Conservatorship for Health Care Decisionmaking," 60 *St. John's Law Rev.* 631 (1986); "Note, Appointing an Agent to Make Medical Treatment Choices," 84 *Col. L. Rev.* 985, 994 (1984); President's Commission, *Deciding to Forego Life-Sustaining Treatment*, pp. 145-47.
16. Collin et al., p. 11.
17. See Collin et al., p. 34; "Note, Appointing an Agent," at 1009-25; President's Commission, *Deciding to Forego Life-Sustaining Treatment*, p. 147; Society for the Right to Die, *The Physician and the Hopelessly Ill Patient* (New York: 1985), pp. 25-26. See also, Uniform Law Commissioners' Model Health-Care Consent Act, Prefatory Note, 9 *U.L.A.* 392 (1982).
18. Arkansas Rights of the Terminally Ill or Permanently Unconscious Act, Act 713 (1987) Cal. Civ. Code §§ 2430-2444 (Supp. 1987); Colo. Rev. Stat. § 15-14-501 (Supp. 1986); Del. Code Ann., tit. 16 § 2502(b); Fla. Stat. Ann. § 765.05(2); Idaho Code § 15-5-501 (Supp. 1986); Iowa Code Ann. § 144A.7(IXa) (Supp. 1986); La. Rev. Stat. Ann. § 40:1299.58.3(cXI) (Supp. 1987); Nevada A.R 467 (June 11, 1987); N.C. Gen. Stat. § 32A-1(9) (Supp. 1985); Pa. Stat. Ann., tit. 20, §§ 5602(aX9), 5603(h) (Supp. 1986); R.I. Gen. Laws § 23-4.10 (1986); Tex. Health Code § 4590h(3Xe) (Supp. 1987); Utah Code Ann. § 75-2-1106 (Supp. 1985); Va. Code §§ 54-325:8:4, 54-325:8:6.2 (Supp. 1986); Wyo. Stat. § 33-26-145(d) (Supp. 1986).
19. Three states, California, Nevada and Rhode Island, have durable power of attorney for health care statutes, while Colorado, North Carolina and Pennsylvania have amended their durable power laws to permit the delegation of health care decisions. The following ten states have provisions in their living will laws that allow the designation of an agent to consent to the withdrawal of life-sustaining treatment: Arkansas, Delaware, Florida, Idaho, Iowa, Louisiana, Texas, Utah, Virginia, Wyoming.
20. New York General Obligations Law § 5-1601.
21. Atty. Gen. Op. F84-16 (Dec. 28, 1984).
22. *Id.*
23. *Id.*

24. See Appendix B, Table H, p. 178-79.
25. Eleven states have statutes that authorize living wills and also specifically permit surrogate decisions about life-sustaining treatment on behalf of incompetent persons who did not express their wishes about treatment in a living will or other form: Arkansas, Florida, Iowa, Louisiana, New Mexico, North Carolina, Oregon, Texas, Utah, Virginia, Washington. See Task Force on Life and the Law, *Do Not Resuscitate Orders*, p. 58, n. 24.
26. See discussion, p. 27.
27. *Id.*

28. The President's Commission discusses several ways in which natural death acts may actually restrict patients' ability to have their wishes honored. See President's Commission, *Deciding to Forego Life-Sustaining Treatment*, pp. 144-45. See also, Richard McCormick and Andre Hellegers, "Legislation and the Living Will," *America*, Vol. 136, 1977, p. 210.

29. No data is currently available about the impact of legislation on the number of persons who sign living wills.

30. Most living will statutes authorize the withdrawal of treatment only from patients who are determined to be terminally ill. Moreover, many statutes do not recognize a person's advance instructions about artificial nutrition and hydration. Courts have held that the constitutional right to refuse treatment will supercede such restrictions. See, e.g., *Bartling v. Superior Court*, 162 Cal. App. 3d 186, 209 Cal.Rptr. 220 (Cal. App. 1984)Xcourt upheld patient's constitutional right to have respirator disconnected notwithstanding his inability to meet "terminal illness" requirement of California Natural Death Act); *Corbett v. D'Alessandro*, 487 S.2d 368 (2d Dist. Fla. 1986)Xcourt affirmed patient's constitutional right to refuse artificial nutrition and hydration notwithstanding inapplicability of Florida living will law to "the provision of sustenance").

31. Among the onerous requirements imposed by living will laws are limitations on the persons who may witness the document (e.g., relatives, heirs, physicians, persons responsible for health care costs); required use of a specific living will form; mandatory notarization or filing of the living will; and a diagnosis of terminal illness as a requirement for signing the document. See Society for the Right to Die, *Handbook 1985*, pp. 28-32 (checklist chart of 36 living will laws). Alexander Capron explained the gap between intention and realization in the living will laws passed to date as follows:

The laudible attempt of many legislatures to give the living will explicit legal recognition has not proven very successful. Beginning with the first such law, the Natural Death Act in California a decade ago, legislative ambivalence over the notion of full-fledged personal autonomy has built self-defeating limitations and outright contradictions into the statutes.

"Legal and Ethical Problems in Decisions For Death," *Law, Medicine & Health Care*, Vol. 14, No.

3-4, Sept. 1986, p. 143. See also, "Choosing How to Die: The Need for Reform of Oregon's Living Will Legislation," 23 *Willamette L. Rev.* 69 (1987).

## **V. The Health Care Proxy: The Agent's Authority, Obligations and Protection**

Appointment of an agent for health care decisions raises a host of issues about the agent's authority: the scope of the authority, how it commences and terminates, and the standards that govern its exercise. The policy questions raised and the Task Force's recommendations are described below.

### **Scope of the Agent's Authority**

Competent adults have a fundamental right to make decisions about their own health care.<sup>1</sup> Individuals may choose to seek treatment for a medical problem or refrain from seeking treatment. They may consent to medical procedures, deny consent, or decide that treatment, once initiated, should be stopped. Within the parameters of their medical plans and ability to pay for medical care, individuals can choose particular physicians or hospitals.

Any policy permitting delegation of this authority must determine what measure of that authority can be transferred to another. It must take into account not only the individual's autonomy, but the dangers inherent in the broad delegation of decisions central to the individual's well-being.

The statutes of other states concerning the delegation of authority for health care decisions address this issue in different ways. In some states, such as Rhode Island, a person may confer full authority for all health care decisions, including decisions about life-sustaining treatment.<sup>2</sup> The only limitations on the agent's authority are those imposed by the person who creates the power and a requirement that the agent make decisions in accordance with what the person would have chosen for himself or herself. In contrast, in California, a person cannot delegate authority to consent to certain specified treatments such as abortion and psychosurgery.<sup>3</sup>

The Task Force believes that competent adults should be free to determine the extent of the authority they wish to delegate. Individuals should be permitted to delegate all the authority they possess or to limit that authority in whatever way they choose. Such a policy recognizes the individual's interest in self-determination and enhances the individual's ability to direct health care matters in accordance with personal concerns, values, and life goals. While a broad delegation of authority creates the potential for abuse, that potential is minimized by the fact that the patient selects the agent and determines the scope of the

agent's powers.

As proposed by the Task Force, the agent's authority may be coextensive with the patient's, but cannot exceed it. Hence, the limitations under existing law concerning the rights of a competent adult would also apply to the agent. Those limitations are not set forth or established in the Task Force's legislative proposal. The Task Force believes that it is not appropriate or necessary to define the rights of competent adults to refuse treatment in legislation about appointing a health care agent.

The Task Force considered whether a health care agent should be prohibited from making certain treatment decisions, either because of the potential for abuse or because decisions about the provision or withholding of the treatment are intensely personal and should rest only with the patient. The Task Force identified the treatments it believes give rise to special concern, including abortion, psychosurgery and artificial nutrition and hydration.

The Task Force concluded that persons should be allowed to appoint someone else to exercise their right to self-determination for these treatments. If a person does not have decision-making capacity when these decisions arise, someone else will have to decide on the person's behalf. The proxy enables a person to choose in advance who that individual will be.

Persons who create a proxy should be informed that general authority to make health care decisions includes authority about these treatments unless the proxy specifies otherwise. In addition, instructions about how to limit the delegation of authority should be part of the instructions for creating a proxy.

**Recommendation**—The Task Force recommends that adults should be able to delegate all or part of the authority they possess to make health care decisions, including decisions about life-sustaining treatment. The proxy form should provide information about the breadth of authority an agent can exercise, and how to limit that authority.

See Proposed Legislation, Section 3.1 and the appendix.

### **The Agent as Surrogate for the Patient**

The premise underlying the appointment of a health care agent is that the agent "stands in the shoes" of the patient. This premise defines the agent's obligations to the patient and the agent's authority in relation to others: health care professionals, medical institutions and the patient's family members.

#### **The Agent's Obligations to the Patient**

Under most statutes concerning the delegation of health care decisions, the agent is required to make decisions consistent with what the patient would have chosen.<sup>4</sup> The Task Force believes that this standard, often referred to as "substituted judgment," should apply.

Under this standard, the agent's decisions should mirror what the patient would have decided for himself or herself; the agent is bound by the patient's intentions as expressed in any written or oral instructions and by his or her knowledge of the patient's values, preferences, and religious and moral beliefs.<sup>5</sup> Thus, if the patient left a living will or written directions in the document appointing the agent, and did not subsequently disavow those

directions, the agent must act in accordance with those wishes. If the agent fails to make decisions that are consistent with what the patient would have wanted, health care professionals, family members or others close to the patient should be able to challenge the agent's authority and, if necessary, seek a court order to terminate that authority.

Generally, the agent is a family member or other person with sustained close contact with the patient. This relationship and the patient's past contact with the agent are invaluable sources of understanding about the patient's wishes and attitudes regarding treatment.

Nonetheless, there may be disagreement on occasion between the agent, family members and health care professionals in interpreting the patient's wishes. Written instructions may be vague or ambiguous, while prior oral statements by the patient and inferences from the patient's general values and life style are susceptible to an even wider range of interpretation. When conflict arises, the agent, by virtue of the patient's designation and good faith efforts, has the moral and legal authority to make a decision. Others who disagree profoundly or believe that the agent is acting irresponsibly may seek a court order. Until an order is issued, the agent should retain lawful authority to act for the patient.

If the patient's wishes cannot be ascertained or inferred in any way, the agent should be obligated to make a decision consistent with an assessment of the patient's best interests.<sup>6</sup> The agent should fashion his or her decision by evaluating the optimal outcome among the range of treatment alternatives. While many medical decisions are necessarily value-laden, the agent should not allow personal beliefs or preferences to interfere with a more objective judgment about the patient's interests. This objective "best interests" standard is often described as a judgment that is consistent with what most people would decide for themselves under the same circumstances.<sup>7</sup>

Regardless of whether the substituted judgment or best interests standard applies, the agent must make certain that the consent provided on the patient's behalf is truly informed. The agent must obtain all relevant medical information about the patient's condition, including the diagnosis, the prognosis, the associated risks and benefits of available treatment alternatives and their costs. The agent must seek necessary medical consultations and ensure that he or she fully understands the medical facts and the consequences of different alternatives for the patient.

### **The Agent's Relationship to Physicians and Family Members**

The foundation for the agent-physician relationship is a shared commitment to the best possible outcome for the patient. This commitment should serve as the basis for a partnership between the agent and the patient's physician. In that partnership, each must respect the separate obligations and authority of the other—the physician as medical expert and advisor and the agent as the patient's surrogate.

In many, if not most, instances, the agent will be a close relative of the patient—a husband or wife, child or sibling. However, some people may prefer to appoint others,

or may have no family members available or capable of serving as agent.<sup>8</sup> In other cases, a person may wish to protect family members from the emotional burden of making difficult decisions, especially if the patient wishes to forego aggressive measures. Finally, the person may be estranged from family members or believe that another person will be more committed to carrying out his or her wishes.

Persons dying from AIDS are more likely to choose someone from outside the family to make health care decisions on their behalf.<sup>9</sup> For this and other reasons, the health care proxy is an especially important instrument for this patient population. Persons with AIDS often are young people, fully capable of making decisions, who face a protracted dying process that usually involves diminished capacity at some point.<sup>10</sup>

The agent's relationship to the family should reflect the patient's own relationship to them and the patient's wishes about their involvement. If the agent is not a member of the patient's family, the agent should request guidance from the patient about the family's involvement when the proxy is created.

Unless the patient instructs the agent not to consult family members, or the agent has strong reasons to believe this would violate the patient's wishes, the agent should remain in close contact with the patient's family. This contact reflects a basic respect for the family relationship and the importance of family members in the patient's life.

Ultimately, however, responsibility for making a decision on the patient's behalf rests solely with the agent. The views of family members should be sought and considered, but the agent must act in accordance with the patient's wishes or, when those wishes cannot be determined, in accordance with a judgment about the patient's interests.

### **Financial Implications of Agent's Decisions**

An agent's health care decisions may result in the provision of expensive medical treatment to the patient. This raises important questions about who pays for the treatment, and whether individuals who have not authorized the treatment can be liable for its cost.

The Task Force believes that a health care decision by an agent should create the same financial obligations as if the decision had been made by the patient. Thus, when an agent consents to treatment, the patient, and more typically the patient's insurer or other third party payer, is obligated to pay for the treatment. The agent should not assume personal liability for the cost of treatment by virtue of granting consent.



While the patient and third party payer will bear primary responsibility for treatment expenses authorized by the agent, the decision may have significant financial repercussions for the patient's family. When an adult household member incurs a major liability, it can seriously affect the family's collective resources. Moreover, under some circumstances, a spouse may be legally responsible for medical and other "necessary" expenses incurred by a financially dependent spouse." Thus, if the agent is not a family member, the financial implications of health care decisions may cause tension and controversy between the family and the agent.

While there is no way to isolate family members from the financial impact of an agent's decisions, the agent's obligation to follow substituted judgment principles directly addresses this concern. In deciding on an appropriate course of treatment, the agent should consider the financial impact on the patient's family to the same extent the patient would have considered this factor in making a decision.

### **Protection from Liability**

The patient entrusts the agent with both far-reaching authority and enormous responsibility. The agent may have to make difficult treatment choices when others have strongly held beliefs about how to proceed. It is important and appropriate that protection from liability extend to all persons who carry out their responsibilities as agent reasonably and in good faith.

Agents should remain personally liable, however, for failing to perform their obligations under the law, such as the duty to make a decision based on reasonably available medical information. Moreover, agents should remain accountable for exceeding their authority under the proxy or for acting for improper or ulterior motives.

**Recommendation**—The Task Force recommends that the agent should be obligated to make health care decisions in accordance with the patient's wishes as expressed in the proxy or in any other manner. If the patient's wishes are not known, the agent's decision should rest on an assessment of the patient's best interests. The agent must obtain all relevant medical information before making decisions on the patient's behalf.

A decision by an agent should create the same obligation to pay for health care expenses as if the patient had made the decision. Finally, protection from civil and criminal liability should be extended to an agent for decisions made in good faith on the patient's behalf.

See Proposed Legislation, Sections 3.2, 3.3, 7.2 and 8.

### **Commencement of the Agent's Authority**

The question of when the agent's authority should begin was considered at length by the Task Force in the course of devising its recommendations for the health care proxy. Should the agent speak for the patient only after the patient has lost the ability to speak for himself or herself or should the agent's authority commence as soon as the proxy is signed? While at first glance the issue appears to be primarily one of procedure, it touches upon values basic to the physician- patient relationship and the art of medicine. It also poses complex questions about how autonomy is best realized in the clinical setting.

The power of attorney traditionally used for financial matters provided the model for the power of attorney or "proxy" for health care. Under most durable power of attorney statutes, designed to allow a person to transact business on another's behalf, the agent's authority commences when the power or proxy is signed.<sup>12</sup> Thus, even while the person who creates the power is capable of making decisions, the agent has the authority to act for the person. When this "immediate power" is used for health care decisions, the patient's participation in the decision-making process is not required because the agent has the authority to consent to treatment.

Many durable power statutes also permit a person to delegate authority that does not begin unless the person loses capacity.<sup>13</sup> This type of power of attorney is sometimes called a "springing" power because it "springs" into effect in the future, when the person who created the power loses capacity. Under a springing power, the agent would not be authorized to make treatment decisions while the patient still has the capacity to do so.<sup>14</sup>

The Task Force considered both the springing and immediate proxy, and whether individuals should be allowed to choose between the two when creating a health care proxy. It also focused

on a third alternative proposed by several Task Force members. Like the immediate proxy, this alternative would permit the agent's authority to begin when the proxy is signed but would require the patient's consent to any decision made by the agent. Under this third option, as long as the patient has the capacity to make decisions, the physician would be required to consult the patient first. If the patient waives the right to decide and requests that the physician consult the agent, the physician would discuss the risks, benefits and alternatives of treatment with the agent. The agent would then reach a decision that would be shared with the patient, at which time the patient would have the authority to approve or reject that decision. For purposes of discussion, this option is called a "consultation proxy."

As the Task Force dialogue on the question unfolded, several factors became increasingly clear. First, the Task Force members embrace the same values and goals for the decision-making process. They strongly believe that patient autonomy should be enhanced and protected and that patients' access to information crucial to treatment decisions must be expanded.

The Task Force members also share certain basic assumptions about the consent process as it now occurs in health care facilities. They believe that physicians all too often do not speak with capable patients or engage in a dialogue with them sufficient to allow a genuine and informed consent. They fear that the very ill or frail are most likely to be excluded from the decision-making process for motives that, even if well-intentioned, may have consequences that are undesirable or dangerous.

The Task Force members also share a deep concern about the difficulty of determining which persons are capable of deciding for themselves about treatment among those who have intermittent, fluctuating and partial capacity. This difficulty is exacerbated by the paucity of procedural guidelines and clinical guidance available to determine capacity. The resulting uncertainty about assessing capacity undermines patients' interest in self-determination and represents a hurdle that must be addressed in any policy for surrogate decision-making.

Thus, the Task Force members brought common values and concerns to their deliberations on the health care proxy. Ultimately, they reached different judgments about how those values should be fostered in policies for commencement of the agent's authority.

At the outset, the Task Force members unanimously rejected the first option, the immediate proxy, as inappropriate for health care decisions and unsound public policy. The immediate proxy

presents grave potential for abuse and seriously undermines the patient's right to decide about treatment by creating the possibility that agents will make treatment decisions without the knowledge or participation of capable patients. Moreover, since the patient and agent both possess decision-making authority, health care professionals would face confusion and uncertainty in the consent process. Should they seek consent from the patient, the agent, or both? Finally, the Task Force believes that many people would want and expect to retain involvement in treatment decisions. They therefore might not understand the implications of creating an immediate proxy or would not choose to do so.

A majority of the Task Force members concluded that health care proxy legislation should permit only a springing proxy. They believe that patient autonomy can be promoted only if the authority to make decisions rests solely with the patient, whenever the patient has the capacity to decide. They also believe that other alternatives would inevitably erode patient autonomy, especially for those most ill and vulnerable, by creating a legal framework that excludes capable patients from the informed consent discussion.

They recognize that the principle of autonomy argues for allowing persons to waive or give away that autonomy. They concluded, however, that in the clinical setting, this option may only exacerbate patient helplessness, encourage dependence and present potential for abuse or pressure on patients to create a proxy that diminishes their own role.

Support for the springing proxy also stems from concerns about the impact of both the immediate and consultation proxy on the relationship between patient and physician. The Task Force members who favor only the springing proxy see the dialogue about treatment between capable patients and their physicians as an indispensable part of the therapeutic process; it gives patients the opportunity to participate as partners in their own care and ensures that they are committed to the course of treatment.

These Task Force members accept and affirm that relatives or others close to the patient often provide invaluable assistance to the patient in the decision-making process. Nonetheless, they believe that this assistance is routinely available without legislative recognition and are concerned that such recognition would shift the physician's focus from the patient to the agent as the source of judgment and authority. Likewise, they recognize that patients may waive their right to decide about treatment under current medical and legal norms.

Indeed, this waiver of consent is expressly recognized by the informed consent statute in New York, Section 2805-d.4(b) of the Public Health Law. They believe, however, that this waiver should not be encouraged by policies embodied in legislation on the health care proxy.

The Task Force members who support the springing proxy as the sole alternative also believe that the consultation proxy would prove impractical and cumbersome in clinical practice. Some physicians would be reluctant or unwilling, for professional and ethical reasons, to engage in a dialogue about treatment with the agent when the patient has decision-making capacity, especially for decisions about life-saving or sustaining measures. Other physicians would feel that they must obtain both the patient's and the agent's consent even if the patient has made a clear choice. Consequently, physicians would face ambiguity in the decision-making process.

Finally, it has been suggested that the springing proxy presents new problems in determining patients' capacity to decide about treatment. The Task Force members who support exclusive reliance on the springing proxy do not agree. Although they recognize that the determination is complex for some patients, they believe that an assessment of the patient's capacity should be made regardless of whether the springing proxy is used. They believe that patients, if capable, should be included in the decision-making process. Hence, the patient's loss of capacity is always an important benchmark, since it should determine whether a patient participates in treatment decisions under a springing, consultation, or immediate proxy.

A substantial number of Task Force members believe that individuals should have the right to choose between the springing and consultation proxy. They believe that allowing persons this option respects personal autonomy and individuals' ability to decide what path best serves their own interests. In essence, they concluded that protecting autonomy means letting people relinquish autonomy when they are too sick or simply reluctant to make treatment decisions.

While these Task Force members also endorse the importance of the physician-patient dialogue, they emphasize that this dialogue remains an unattained ideal for many patients in certain health care settings. They are deeply concerned that the consent process for marginally competent patients now has little content; it is a formality that rubber stamps the physician's decision with the signature of a patient who may or may not have comprehended

the nature of the decision made. Hence, they believe that a dialogue with an appointed agent, who is unimpaired by the vulnerability and limitations that illness imposes, provides more meaningful protection for the patient. The agent serves as advocate for the patient throughout the process, while the patient retains the right to approve or reject the agent's choices.

The Task Force members who support the consultation proxy also believe that the process is workable and that it mirrors the way the decision-making process now takes place in many cases when patients waive consent or need the assistance of family or friends. Indeed, they believe that the process protects patients well beyond the norms accepted in medical practice since it requires an explicit waiver by the patient of the right to decide and express approval of the agent's decision. It thus circumscribes the authority now implicitly or explicitly vested in family members when patients are very ill or possess only fluctuating or marginal capacity. They recognize that neither the patient's waiver nor participation by family members or close friends in the decision-making process are precluded under existing law; but they believe that the process proposed should be granted legal sanction.

Finally, they believe that the consultation proxy is a better option for some patients because it permits the agent to act without requiring a determination that the patient lacks capacity. It also would avoid the need to inform patients that they have been determined to lack capacity. It may be very difficult for health care professionals to assess the capacity of some patients. Moreover, in some cases, patients may simply not want to be informed of their own diminished capacities.

The majority of the Task Force members—those who favor only the springing proxy—also believe that there is a large gap between theory and practice in the informed consent process. They too recognize that certain patient groups, such as the frail elderly in long-term care facilities, are especially vulnerable. Nonetheless, they believe that the health care proxy should be structured to achieve the purpose that fueled creation of advance directives—the establishment of a decision-making process for patients without capacity. The problems associated with informed consent, especially in the long-term care setting, are complex. These problems demand rigorous scrutiny and public attention. The majority of the Task Force members believe that they should be addressed by separate educational, regulatory or legislative initiatives.

Regardless of where the Task Force members stand on the question of when the agent's authority begins, they all strongly believe that health care proxy legislation is needed to protect the interests and rights of individuals in New York State. They do not see their difference in judgment on this single question as a stumbling block to legislative action. Instead, they submit the matter to the public for debate and resolution as the health care proxy legislation is considered by the Legislature and the public at large.

***Recommendation***—The Task Force recommends that the agent's authority should commence upon a determination that the patient lacks capacity to make health care decisions.

See Proposed Legislation, Section 2.4.

### **Capacity to Make Health Care Decisions**

Whether or not the patient creates a health care proxy, the loss of decisional capacity is a critical milestone in the patient's care and the process for making treatment decisions. The standard to determine decisional capacity and the process by which such determinations are made must therefore be carefully defined and implemented.

The same is true when a springing power is used. In this context, the determination that the patient lacks capacity triggers the agent's authority. The procedure must be structured so that health care providers and the agent can be certain when the agent has legal authority to act.

#### **The Standard for Capacity**

In recent years, the notion of capacity to make health care decisions has emerged as an alternative to the traditional standard of competence.<sup>15</sup> While used in many contexts, "competence" refers most accurately to a judicial determination about a person's decision-making ability. Moreover, competence generally describes a status, the ability to make all or, conversely, no decisions for oneself. In contrast, "capacity" is a more limited and specific concept; it refers to a person's ability to make a particular decision as determined by health care professionals or others.

First proposed by ethicists and philosophers, the notion of capacity has gained the support of numerous organizations, including the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research.<sup>16</sup> The Task Force, in its report on do-not-resuscitate orders, issued in April of 1986, proposed that the capacity standard should be applied in the context of decisions about resuscitation.<sup>17</sup> More recently, the New York Court of Appeals adopted the standard in its 1986 decision, *Rivers v. Katz*.<sup>18</sup>

While the capacity standard has been widely accepted, it is new and its practical implications have not yet been fully explored. As the Task Force developed its recommendations for the appointment of a health care agent, it recognized that the capacity standard's theoretical appeal and the added protection it offers patients must be balanced against the clinical demands of medical care delivery.

If the standard is applied literally, a determination that a patient lacks capacity would only establish the patient's inability to make a particular treatment decision. For patients who unquestionably lack capacity, such as those who are permanently unconscious or have a severe mental impairment, successive determinations of capacity for each treatment decision would be unnecessary. However, even for those patients who might have marginal or limited capacity, it is neither desirable nor possible to re-evaluate the capacity of every patient in connection with every medical treatment.

This is especially true where the determination serves to trigger the authority of a health care agent appointed by the patient. Rigid adherence to a treatment-specific notion of capacity would drastically undercut the usefulness of a health care proxy, since a re-evaluation of the patient's capacity would be required before obtaining the agent's consent to any treatment. Instead of requiring this re-evaluation, the Task Force concluded that appropriate safeguards should be provided to protect the patient's right to object to the determination or to re-assert authority over treatment decisions.

For purposes of a health care proxy, the Task Force believes that the capacity standard should encompass the ability to make health care decisions generally. As proposed by the Task Force, that definition would refer to the ability to understand and appreciate the nature and consequences of health care decisions, including the benefits and risks of any proposed treatments, and to arrive at an informed decision. Upon a determination that a patient lacks capacity, the agent should be empowered to make all health care decisions on the patient's behalf, until such time as the patient either regains capacity or revokes



the proxy.

Nonetheless, there are circumstances when the patient's capacity should be re-evaluated. The need for a re-evaluation is most apparent when there is a change in the patient's condition that would affect the patient's decision-making ability. Even if the patient's condition does not change, a re-evaluation of capacity will sometimes be warranted when new treatment decisions arise.

It is neither practical nor possible to list the circumstances where the capacity determination should be re-evaluated. This should remain a matter of clinical judgment. However, such judgment should include consideration of: (i) the nature of the interest at stake; (ii) the complexity of the decision, including the treatment alternatives; and (iii) the safeguards available to protect the patient's right to oppose the determination or the proposed course of treatment.<sup>19</sup>

### **The Process for Determining Capacity**

In New York State, the only procedures to determine capacity that have clear legal recognition are judicial proceedings or, for persons who are in certain mental health facilities, hearings brought under Article 80 of the Mental Hygiene Law.<sup>20</sup> Formal procedures are necessary when the person's right to make health care decisions is at stake. The Task Force believes that a simpler procedure is appropriate where the sole purpose of the determination is to initiate the agent's authority under a health care proxy.

The Task Force proposes a hospital-based procedure to assess the patient's capacity and determine when the agent's authority should commence. Under this procedure, the patient's attending physician would make the determination that the patient lacks capacity and would state the reasons for the determination in the patient's medical record.<sup>21</sup> Requiring a statement of reasons promotes well-founded decisions and enables those affected to understand and challenge the determination.

The patient should then be informed of the determination of incapacity. Without this notification, patients would be denied the opportunity to object and the right to oppose the determination or the treatment decision at issue. Some persons who lack decision-making capacity, such as those who are unconscious or severely brain damaged, are incapable of understanding any notice given to them. If the patient does not have the ability to comprehend information about the capacity determination, notification would

be a meaningless gesture that should not be provided.

A person who creates a proxy extends the right to decide to another. The person does not, however, relinquish the right to make health care decisions on his or her own behalf. As proposed by the Task Force, a determination by the attending physician that the patient lacks capacity would not terminate the patient's right to make health care decisions, nor would it affect the patient's right to revoke the agent's appointment. Thus, if the patient objected to the determination of incapacity or to the agent's exercise of authority, the patient could revoke the proxy or inform health care providers of his or her treatment decision. Health care professionals, family members or others close to the patient who believe that the patient lacks capacity and wish to override the decision would have to seek a judicial finding that the patient lacks capacity.<sup>22</sup>

If the patient regains the ability to make health care decisions, the agent's authority under the springing power should lapse. After regaining capacity, the patient should not be required to execute another proxy; the proxy should become operative again if the patient subsequently loses capacity. For patients who are subject to intermittent periods of incapacity, this process provides needed flexibility and protects the patients' interest in self-determination.

### **Tests to Determine Capacity**

As the Task Force observed in its report on do-not-resuscitate orders, there are no settled medical guidelines about the tests and procedures to determine a person's capacity to make health care decisions. Practices vary considerably among institutions, ranging from psychiatric testing to informal evaluations based on casual examination. Moreover, few health care facilities in the State have written guidelines for the capacity determination. Of 136 hospitals that responded to a question about the determination of capacity on a survey conducted by the Task Force, only 29% stated that they have written guidelines for determining capacity. Of the 196 nursing homes that responded, only 13% have written guidelines.<sup>23</sup>

In light of increasing public concern about surrogate decision-making and the vital interests denied once a patient is determined to lack capacity, it is clear that further study and understanding is needed in this crucial area. The Task Force urges the medical community to study the measures used to determine decision-making capacity and to develop appropriate

guidelines.

***Recommendation***— An informal hospital-based procedure should be used to determine that the patient lacks capacity to make treatment decisions and that the agent's authority under a health care proxy should commence. The procedure should involve a written determination by the patient's attending physician. Both the patient and the agent should be informed of the determination.

The informal determination should initiate the agent's authority, but should not deny the patient's right to make health care decisions if the patient objects to the determination of incapacity or to the agent's treatment decision. If the patient regains decision-making capacity, the agent's authority should lapse.

See Proposed Legislation, Section 4.

## Footnotes

1. See discussion, Chapter fl.
2. R.I. Gen. Stat. § 23-4.10-2.
3. Cal. Civ. Code § 2435.
4. See, e.g., Cal. Civ. Code § 2434(b); R.I. Gen. Stat. § 23-4.10-2.
5. For a discussion of the standard of substituted judgment and its application, see Lawrence Schneiderman and John Arras, "Counseling Patients to Counsel Physicians on Future Care in the Event of Future Patient Incompetence," *Ann.Int. Med.*, Vol. 102, No. 5, May 1985, pp. 693-98; Robert Veatch, "An Ethical Framework for Terminal Care Decisions; A New Classification of Patients," *JAm.Ger.Soc.*, Vol. 32, No. 9, Sept. 1984, pp. 665-69; Robert Veatch, "Limits of Guardian Treatment Refusal: A Reasonableness Standard," *Am.J.Law & Med.*, Vol. 9, No. 4, 1984, pp. 427-68. This standard is also discussed by the President's Commission, *Making Health Care Decisions*, Vol. 1, pp. 177-79, and *Deciding to Forego Life-Sustaining Treatment*, pp. 132-34.
6. As the Task Force recognized in its report, *Do Not Resuscitate Orders* (April 1986), p. 44, there is no sharp line between the substituted judgment and best interest standards. The New Jersey Supreme Court in *Matter of Conroy* acknowledged this when it broke the best interest standard into two strands: the "limited-objective" and "pure objective" tests. The former takes account of "trustworthy evidence" that the incompetent patient, if competent, would refuse treatment, when the evidence is too vague to constitute clear proof of the patient's wishes. The pure objective test applies to cases where no meaningful indication of the patient's wishes exists. 486 A.2d at 1229-33. For a discussion of the best interests standard, see Schneiderman and Arras, p. 695; Veatch, "Limits of Guardian Treatment Refusal," pp. 440-41; Norman Cantor, "Conroy, Best Interests and the Handling of Dying Patients," 37 *Rutgers L. Rev.* 543-77 (1985).
7. See President's Commission, *Deciding to Forego Life-Sustaining Treatment*, pp. 134-36; Veatch, "Limits of Guardian Treatment Refusal," pp. 440-41.
8. A Harris poll conducted for the President's Commission asked, "If you were too sick to make an important decision about your medical care, who would you want to make the final decision for you?" Of those polled, 57% said they would prefer a family

member; 31% chose their doctor; 6% said a doctor who was a family friend; 2% said a close friend; and 2% chose their lawyer. The remainder (1%) named others or said they were not sure. President's Commission, *Making Health Care Decisions*, Vol. 2, p. 240.

9. A study of homosexual AIDS patients in San Francisco found that 47% of these patients would choose their partners or friends as proxy decision-makers, 32% would select family members, and 14% would choose their physicians. See Robert Steinbrook, Bernard Lo, Jeffrey Moulton, Glenn Saika, Harry Hollander and Paul Volberding, "Preferences of Homosexual Men with AIDS for Life-Sustaining Treatment," *NEJM*, Vol. 314, No. 7, Feb. 13, 1986, pp. 457-60.

10. *Id.* See also, Michael MacDonald, Kathryn Meyer and Beth Essig, *Health Care Law: A Practical Guide*, (New York: Matthew Bender, 1987) pp. 18-55.

11. See *In re Burt's Will*, 254 App. Div. 584, 3 N.Y.S.2d 70 (2d Dept. 1938); 47 N.Y.Jur.2d §§ 696, 698.

12. E.g., New York General Obligations Law § 5-1601. See Uniform Durable Power of Attorney Act, 8A U.L.A. 1 (1979).

13. E.g., Cal. Civ. Code § 2400 (Supp. 1987); Mass. Gen. Laws Ann., c. 201B, § 1 (1986); N.J.S.A. 46:2B-8. See Uniform Durable Power of Attorney Act, *supra*.

14. For example, California's Durable Power for Health Care Act provides that an agent may not make a decision for which the principal is able to give informed consent unless the principal expressly provides otherwise in the durable power. Cal. Civ. Code § 2434(a). Nevada's new law similarly authorizes an agent to make health care decisions only if the principal becomes incapable of giving informed consent regarding such decisions. A. R 467, § 3. The Rhode Island Health Care Power of Attorney Act does not expressly state when the agent's authority commences. See R.I. Gen. Stat. § 23-4.10-2. Under the eleven living will statutes that authorize the appointment of an agent for decisions about life-sustaining treatment, the agent's authority becomes effective when the patient is incapable of making a decision for himself or herself. See, e.g., Iowa Code §§ 144A.1 (1986); Tex. Stat. Ann. art. 4590h (1986).

15. For a more extensive discussion of the limitations of the competence standard, see Willard Gaylin, "Competence, No Longer All or None," in *Who Speaks for the Child: The Problems for Proxy Consent*, Willard Gaylin and Ruth Macklin (eds.) (New York:

Plenum

Press, 1982), pp. 27-54; Charles Culver and Bernard Gert, *Philosophy in Medicine* (New York: Oxford University Press, 1982), pp. 20- 63. Ruth Faden and Tom Beauchamp explain the need for a concept of “task oriented competence” in *A History and Theory of Informed Consent* (New York: Oxford University Press, 1986), pp. 288-290.

16. President’s Commission, *Deciding to Forego Life-Sustaining Treatment*, pp. 121-70.

17. Task Force on Life and the Law, *Do Not Resuscitate Orders*, p. 26.

18. 67 N.Y.2d at 497.

19. As the President’s Commission states, “A conclusion about a patient’s decision-making capacity necessarily reflects a balancing of two important, sometimes competing objectives: to enhance the person’s well-being and to respect the person as a self-determining individual.” *Making Health Care Decisions*, p. 57. Several authors suggest that the standard to determine capacity should vary according to the interests at stake. They argue that a lesser standard should apply to decisions of minimal consequence, with more stringent standards applying as the potential consequences increase. See Gay- lin, pp. 27-54; James Drane, “Competency to Give Informed Consent: A Model for Clinical Assessments,” *JAMA*, Vol. 25., No. 7, Aug. 17, 1984, pp. 925-27; Loren Roth, Alan Meisel, and Charles W. Lidz, “Tests of Competency to Consent to Treatment,” *Am.J.Psychol.*, Vol. 134, No. 3, March 1977, pp. 279-84; Mark Munetz, Charles Lidz, and Alan Meisel, “Informed Consent and Incompetent Medical Patients” *J.Fam.Prac.*, Vol. 20, No. 3, 1985, pp. 273-79. However, Edmund Pellegrino argues that a “situation-based scale” confuses the competency [capacity] of the patient with the competency of the decision” and creates a rationalization for imposing a decision upon a patient. “Informal Judgments of Competence and Incompetence,” (in press).

20. See discussion, pp. 25-26.

21. The procedure to determine capacity is less rigorous in this context than the procedure the Task Force recommended in its proposal regarding the issuance of do-not-resuscitate orders. See Task Force on Life and the Law, *Do Not Resuscitate Orders*, p. 31. Under a health care proxy, a determination of incapacity triggers the agent’s authority under circumstances to which the patient

agreed when the proxy was signed. In the Task Force's proposed legislation on do-not-resuscitate orders, a determination could empower a surrogate to make a decision about resuscitation in situations where the patient had not agreed to, or even anticipated, a surrogate decision. In that context, the surrogate's authority to decide about resuscitation is derived entirely from statute, and not from the patient's consent. Greater procedural protections for the determination of capacity are therefore provided in those circumstances.

22. *Rivers v. Katz*, 67 N.Y.2d 485 (1986), establishes that a patient has a constitutional right to make treatment decisions and that a judicial finding of the patient's lack of capacity is ordinarily needed before treatment may be imposed over a patient's objection. Thus, a physician's determination of incapacity, while sufficient to trigger the authority of an agent, is not a constitutionally adequate basis for overriding treatment decisions made directly by the patient.

23. See Appendix B, Table B, pp. 170-71.





## VI. Creating A Health Care Proxy

### **Competence To Appoint a Health Care Agent**

Under New York law, adults are presumed competent to manage their own affairs unless determined otherwise by a court.<sup>1</sup> Thus, persons not adjudged incompetent have the authority to convey property, enter into contracts, create powers of attorney, and incur other legal obligations.<sup>2</sup> The Task Force believes that the right to create a health care proxy should be available on the same basis—adults should be presumed to have the authority to create a health care proxy unless determined otherwise in a court proceeding.

The Task Force therefore recommends that all competent adults should have the right to appoint a health care agent. It proposes competence, rather than capacity or another standard, as the criterion for creating a proxy because of the formality of the procedure to determine incompetence and the safeguards accorded individuals in that process.

The term “incompetence” connotes a judicial determination of the person’s decision-making ability. In contrast, capacity generally refers to a determination by health care professionals or others arrived at by less formal procedures. As proposed by the Task Force, these nonjudicial determinations would not deprive a person of the right to create a proxy or make health care decisions, although they may serve other important functions. The requirement of a judicial process to terminate a person’s right to make health care decisions reflects constitutional protections as well as a basic respect for individuals and their right to control decisions about their own bodies.<sup>3</sup>

***Recommendation***—A competent adult should have the right to appoint a health care agent. All adults should be presumed competent unless determined otherwise by a court.

See Proposed Legislation, Section 2.1.

### **Selecting The Agent**

Attainment of a person’s health care goals is largely dependent on the agent’s ability and commitment to further those goals on the person’s behalf. In selecting an agent, it is most important

that persons designate someone they trust to act in accordance with their stated wishes, values and interests. Moreover, persons who serve as agents must have the ability to understand medical information provided and to act as an advocate for the person in seeking information. An agent must also be accessible and willing to exercise the profound responsibility of making treatment decisions.

Allowing a person broad discretion in designating an agent protects and affirms the person's right to self-determination in this very personal choice. Nonetheless, an individual's freedom of choice in designating an agent should not be absolute. The agent is given broad, indeed, extraordinary power over a patient's care. Authority to direct the withdrawal of life-sustaining treatment is only one, although perhaps the most striking, example of the agent's authority. It is particularly important, therefore, that the agent is not influenced by conflicting interests—interests which might cause the agent to make decisions contrary to the patient's wishes or well-being.

Some conflict of interest situations must and should be tolerated. For example, a person's spouse or children might be beneficiaries under the person's will or insurance policy, or might be liable for the costs of the person's treatment. Yet many people would choose a spouse or other family member to act on their behalf and would expect them to make decisions that reflect their wishes, despite any real or potential conflict of interest. Indeed, reliance on close family members as surrogate decision-makers is strongly supported by our social and medical traditions.

Other conflicts, however, are more problematic. For example, when administrators or employees of a health care facility serve as agents for patients at the facility, they may be subject to institutional pressures. Hence, they may be unwilling to make medical choices that violate institutional policies or thwart the facility's interests. Indeed, if such persons are permitted to serve as agents, facilities may encourage patients to appoint them for purposes of administrative convenience.

Concerns also arise when a physician acts as a health care agent. Physicians who serve as agents seek consent at the same time they have the power to withhold or grant it. In some cases, a physician's professional ethos may overwhelm a patient's preferences. Equally important, a physician may have an immediate financial interest in the provision or withholding of treatment.

The Task Force recognizes that some persons will want to select their physician as agent. It also acknowledges that every restriction on the persons who may serve as agent diminishes the self-determination of those seeking to create a proxy. Nevertheless, the Task Force believes that a person should not be permitted to act simultaneously as the patient's attending physician and health care agent; the situation is fraught with potential for conflict and abuse.

In some cases, the physician designated as agent will not be responsible for the patient's care when authority under the proxy is triggered. However, if the physician does have primary responsibility for the patient's care when the patient loses capacity and authority under the proxy commences, the physician should be required to choose between serving the patient as attending physician or as health care agent. Persons who appoint their physician as agent should therefore be urged to select an alternative agent in the event that the physician chooses to remain their primary physician when the authority under the health care proxy commences.

***Recommendation***—The Task Force recommends that operators, administrators and employees of health care facilities should not be permitted to serve as agent for a patient at their own facility, unless they are a member of the patient's family or were appointed as agent prior to the patient's admission to the facility.

The Task Force further recommends that a physician should not be permitted to act simultaneously as a patient's attending physician and health care agent. Where such a conflict arises, the physician must choose between assuming the role of agent and serving as the patient's attending physician.

See Proposed Legislation, Section 2.3.

### **The Proxy Form**

The form used for the health care proxy must serve several essential functions. First, the form should explain the purpose of the proxy and the nature and scope of the authority delegated to the agent. This function is crucial; for some individuals, the form will constitute the primary or sole source of information about the proxy.

Second, the form should assist individuals to create a proxy that is legally valid and effective. For example, it should provide instructions about the witness and other requirements so that persons can create a proxy without the need to consult a lawyer. It should also

explain how to provide health care instructions to the agent. Finally, the form must give the agent and health care providers clear guidance about the agent's authority and obligations.

The value of prescribing a proxy form which can be used to appoint an agent is apparent. A more difficult question concerns whether a single proxy form should be mandated as the only lawful form to appoint a health care agent. When a single form is mandated, everyone who creates a proxy is exposed to the warnings and guidance the form provides. It also increases the likelihood that the completed form will be legally sufficient and assures health care providers of the document's validity.

There are disadvantages, however, if legal recognition is granted to only one proxy form. While measures can be taken to make any standard form widely available, the form will not be accessible to all individuals prior to hospitalization. Moreover, some people may create non-conforming proxies without realizing that they are required to use a particular form. When this occurs, their appointment would be invalid. Indeed, many people in this State may have already used one of the popularly available living will/power of attorney forms.

The Task Force concluded that the burdens of a mandated form outweigh the benefits. Persons who appoint a health care agent in a document that provides essential information and instructions should not be penalized if the document does not conform to a prescribed text.

The need to ensure the integrity of nonconforming proxies can be served by requiring that all proxies are properly signed and witnessed and contain certain basic information, such as: (i) the agent's name; (ii) the nature of the authority given to the agent; and (iii) the fact that the authority commences upon a determination of the person's incapacity. Nonetheless, a proxy that departs substantially from forms that are widely used and recognized, may be challenged or may not be honored. Far-reaching efforts should therefore be made to facilitate access to a standard proxy form. At a minimum, the forms should be routinely available at physicians' offices, hospitals, nursing homes, clinics, and other health care institutions. Broad distribution of the proxy form will encourage its use and reduce the possibility that individuals will appoint an agent in a manner that is legally deficient.

**Recommendation**—The Task Force's legislative proposal includes a proxy form that may but need not be used to appoint an agent. The form provides information about the potential scope of the agent's authority, especially as it relates to certain critical treatment decisions. The form also describes various options and rights accorded persons creating a proxy, including the right to override decisions by the agent and to revoke the proxy. Finally, the form explains how to create a proxy and assists individuals to identify any special provisions necessary to accomplish their personal health care objectives. The Task Force recommends that the Commissioner of Health take the steps necessary to assure that standard proxy forms are widely distributed to New York State residents.

See Proposed Legislation, Section 2.5 and the appendix.

### **Drawing Up a Health Care Proxy**

The process to draw up a health care proxy should ensure the integrity of the document by promoting informed voluntary choices by the person who signs it. The process should also compel the person creating the proxy to consider the seriousness of the proxy, the powers granted, and the significance of delegating those powers. Later, others must be certain that the person whose signature appears on the proxy actually signed it and that the person appeared to act in a knowing and voluntary manner in doing so.

The value of safeguards for creating a proxy must be balanced against the interest in preserving a simple means to appoint an agent. Complex or burdensome procedures to draw up a proxy will increase the likelihood that many proxies will prove invalid when needed. Moreover, any such process should not require legal assistance, since those who cannot afford legal help would effectively be denied use of the proxy.

Persons who create a proxy should discuss the proxy with a physician or another health care professional such as a nurse or social worker. This dialogue with a health care professional is critical. It should enable persons to understand the nature and range of decisions that may be made on their behalf as well as the kind of medical conditions, such as permanent loss of consciousness, under which they might want decisions to be made about life-sustaining treatment. A dialogue with health care professionals also greatly enhances the possibility that the person will fashion specific instructions for the agent.

Persons who draw up a proxy should also be urged to discuss the proxy and their health care preferences with their appointed agent. This discussion makes the proxy a more meaningful delegation and a better vehicle to promote the person's control over health care decisions. It also gives the agent an opportunity to ask questions and to understand the person's concerns more fully.

The Task Force has devised a process for creating a health care proxy that provides essential safeguards without imposing an undue burden. First, the person should sign the proxy or direct another to sign it on his or her behalf. The option of having another sign for the person creating the proxy should be available, since some adults with decision-making capacity cannot sign documents as a result of physical disability.

The proxy should be signed by two adult witnesses. The witnesses should attest to the fact that the person appeared to be of sound mind and free from duress. This adds a common sense, empirical safeguard. The witnesses need not have expert qualifications or the ability to make medical or legal judgments.

Under some state laws, certain categories of persons are disqualified from witnessing a living will or health care proxy, e.g., health care providers, relatives, or others who have a financial interest in the patient's course of treatment.<sup>4</sup> Restrictions on the persons who may act as witnesses are designed to make it more difficult for someone with a conflicting interest either to coerce a person into creating a proxy or to falsify a proxy.

The Task Force believes that excluding family members and health care providers from witnessing a proxy imposes a burden on those who wish to create a proxy without yielding a commensurate benefit in eliminating abuses. The exclusion of family members is particularly objectionable, since it disqualifies the individuals many persons would choose to act as witnesses and those most likely to be available if questions about the circumstances surrounding the proxy's creation arise.

The Task Force believes, however, that the person appointed as agent should be prohibited from witnessing the proxy. This addresses the most serious potential for abuse—coercion or fabrication by the person appointed as agent in the process to create a proxy.

Residents of nursing homes and mental health facilities are especially vulnerable to abuses concerning the creation and use of health care proxies. In particular, they might be induced to appoint a health care agent without fully comprehending the significance of the document or its implications for them. For this reason, the Task Force recommends special safeguards when proxies are created in longterm care or mental health facilities. Those safeguards are discussed in Chapter VIII below.

**Recommendation**—A person should be able to appoint an agent with a written proxy, signed by or at the person's direction. The person's signature should be witnessed by two adults, who should affirm that the person appointing the agent appeared to be of sound mind and free from duress.

The person appointed health care agent should not act as witness to execution of the proxy. Special measures, described in Chapter VIII, should be required for proxies created by residents of nursing homes and mental health facilities.

See Proposed Legislation, Sections 2.2 and 11.  
**Ending the Proxy**

### **Revocation**

Once a proxy is created, revocation of the proxy is the primary means for a person to reassert control over health care decisions. There are many reasons why a person might wish to revoke a proxy, including disagreement with the agent's decisions or a desire to appoint someone else to serve as agent.

Revocation of the proxy must be a simple process so that individuals will not be thwarted in their efforts to regain control over their health care. The Task Force believes that a person should be able to revoke a proxy by notifying the agent or a health care provider of the wish to revoke, orally or in writing, or by any other act that conveys the intent to revoke the proxy. For example, the proxy should be revoked if the person destroys or defaces the document. The Task Force also proposes that the proxy should be revoked automatically when a person signs a subsequent proxy or when the person is divorced or legally separated from a spouse who had been appointed agent.

All persons should be presumed competent to revoke a proxy unless determined otherwise by a court. The determination of incapacity that triggers an agent's authority under a proxy is not sufficient to deprive a patient of the right to revoke the proxy.

Revocation of the proxy must be distinguished from a patient's wish to override the agent's decision when the patient and the agent disagree. While both are extensions of the individual's right to control the course of his or her health care, revocation of the proxy ends the agent's authority completely. In contrast, when a patient overrides a particular decision by the agent, the agent's authority to make other decisions remains unimpaired.

### **Expiration**

The Task Force considered whether the proxy should expire automatically after a specified period of time. Mandatory expiration is designed to protect people who create a proxy from the legal recognition of wishes that were expressed years earlier and may not reflect the person's current preferences.

Nonetheless, automatic expiration of the proxy has serious drawbacks. Persons who want and expect their agent to be empowered to make decisions for them will have their wishes denied if they inadvertently fail to renew the proxy. Thus, automatic expiration will often reduce, rather than increase, the likelihood that a person's actual wishes will be honored. In recognition of the problems created by requiring that the proxy expire after a fixed time period, two states—Georgia and Wisconsin—recently amended their living will statutes to remove the expiration provisions.<sup>1</sup>

The Task Force concluded that the expiration requirement poses greater potential for harm than the problem it is designed to address. In addition, mandating automatic expiration is unduly paternalistic. It is reasonable to expect persons who create a proxy to assume responsibility for updating or revoking the proxy when necessary to reflect their current wishes. A proxy should not be distinguished in this regard from other legal documents such as a will, trust or financial power of attorney.

**Recommendation**—The Task Force recommends that a person be allowed to revoke a health care proxy by notifying the agent or a health care provider, orally or in writing, or by any other act that conveys the intent to revoke the proxy. The proxy should be revoked automatically if the person creates a subsequent proxy but should not expire automatically after a specified time period. See Proposed Legislation, Section 6.



## Footnotes

1. 27 N.Y.Jur. Incompetent Persons §§2, 6.
2. See *Winters v. Miller*, 446 F.2d 65, 68 (2d Cir. 1971); *Sengstack v. Sengstack*, 4 N.Y.2d 502, 176 NYS.2d 337, 151 N.E.2d 887 (1958). However, prior actions of persons adjudged incompetent may be found voidable once incompetency is judicially established. 27 N.Y.Jur. Incompetent Persons § 52.
3. See *Rivers v. Katz*, 67, N.Y.2d 485 (1986). As explained by James Childress,  

To override a person's wishes, choices, or actions without "due process" is to deepen the affront to dignity. The sort of procedures required will vary according to the rights at stake, such as the deprivation of liberty. If it is not possible to develop reliable procedures that can express both care and respect, even limited paternalism may not be acceptable in practice.

James Childress, *Who Should Decide?: Paternalism in Health Care* (New York: Oxford Univ. Press 1982), p. ix.
4. E.g., Cal. Civ. Code § 2432(d); Del. Code Ann. title 16 § 2503; Texas Stat. Ann. article 4590h; R.I. Gen. Stat. § 23-4.10-2.
5. Ga. Code Ann. § 31-32-6 (Supp. 1986); Wise. Stat. §§ 154.03 (Supp. 1986).



## **VII. The Obligations of Physicians and Other Health Care Professionals**

### **The Physician-Agent Relationship**

When a determination is made that the patient lacks capacity and the agent is authorized to make health care decisions on the patient's behalf, the patient-physician relationship changes. While the physician's commitment to the patient's well-being remains undiminished, other obligations are transformed and require that the physician relate to the agent in a manner that promotes the patient's welfare.

When an agent has authority under a health care proxy, the physician must still seek informed consent. However, it is the agent, not the patient, who must be fully informed to make treatment decisions.

The physician should always provide a complete and straightforward explanation of the relevant medical circumstances to the agent. That explanation should include a discussion of the risks and benefits of any proposed treatment, as well as information about available alternatives. While it is also appropriate for the physician to offer guidance, that guidance must be distinguished from a clear statement of the medical facts necessary for the agent to make an informed judgment on the patient's behalf.

As a practical matter, when a patient lacks capacity, the physician usually approaches the most accessible family member to obtain consent and thereby determines who speaks for the patient. When the patient has appointed a health care agent, the physician has neither the responsibility nor the right to decide who should make decisions for the patient.

The creation of a health care proxy vests the agent with the moral and legal authority to act on the patient's behalf. Consent by the agent should authorize the same procedures and give rise to the same obligations and protections for health care providers as if the patient had consented to treatment. Unless the patient regains capacity or has withheld authority from the agent for particular decisions, the physician must be guided by the agent's choices, provided that the agent acts in good faith and has the capacity to serve.

Thus, an agent's decision may override the family's preference or the physician's recommendation. While physicians may seek to inform and persuade an agent, they cannot simply substitute their own judgment for that of the agent.

In some cases, physicians may not only disagree with the agent's decision, but may believe that the chosen course of treatment violates their own moral or professional code. When this occurs, physicians have the same obligations they would have if it were a patient's decision to which they objected. The physician should first discuss the issues with the agent in an effort to reach a mutually satisfactory resolution. If this dialogue fails to resolve the matter, the physician must either transfer care of the patient to a physician whose values are more compatible with the patient's or seek a court order to override the decision.

Transferring care of the patient, however, is not appropriate when the physician believes that the agent is incapable of acting on the patient's behalf. The attending physician has an obligation to the patient to intervene when an agent is unable or unwilling to fulfill his or her responsibilities.<sup>1</sup>

Several conditions must be met for the agent to act responsibly on the patient's behalf: the agent must (i) be adequately informed; (ii) have the capacity to understand the information and make reasoned decisions based on that information, and (iii) act in good faith. If any of these conditions are not met, the physician should serve as an important check and balance to the agent's authority.

If the agent lacks the necessary medical information to make an informed choice, the physician should explain all the relevant medical facts. An unsound decision by an agent may well be changed by a dialogue with the physician or other health care professionals. If a physician believes that the agent's decision violates the patient's expressed wishes, the physician may involve other persons concerned about the patient to assure that the agent makes a better assessment of the patient's preferences and values.

In some situations, however, an agent may be simply incapable of carrying out the responsibilities under a proxy. In still other circumstances, the physician may believe that the agent's decisions or behavior indicate that the agent is acting in bad faith and pursuing personal interests, rather than those of the patient. In either case, the physician should involve family members and hospital administrators. If necessary, the physician or someone else close to the patient should seek judicial relief to remove the agent.

## **Communicating with the Patient**

Although some people who lack decision-making abilities are not able to communicate at all, other persons are capable of conversing, on some level, about their condition and care. Indeed, they often have questions and concerns and may have important information to offer. The existence of a health care agent, therefore, does not relieve health care professionals of the obligation to communicate with the patient to the extent the patient is able to understand the information provided.<sup>2</sup>

Patients should also be encouraged, to the extent they are able, to make non-medical decisions about their care. Allowing a patient to decide, for example, whether to take two injections at once, or one in the morning and one at night, respects the patient's autonomy and may enhance a sense of control and self-esteem. It also reinforces the decision-making abilities of patients who may be able to regain capacity.

## **Informing the Health Care Team**

Once the proxy is signed, a physician who treats a patient on an ongoing basis should be given a copy of the proxy and advised of the agent's name, address, telephone number and relationship to the patient. The physician should record this information in the patient's medical record, at the appropriate office, clinic, or hospital.

The patient's primary physician has an obligation to bring the proxy to the attention of other health care providers who treat the patient. This is especially important for a patient who has lost decision-making capacity. Whenever the patient is referred to another physician, the agent's name, address, telephone number, and relationship to the patient should be included in the referral information. Likewise, when a patient is admitted to a hospital, this information should be part of the admitting data so that members of the medical and nursing staffs caring for the patient will know immediately who to approach for consent to treatment.<sup>3</sup>

## Protection from Liability

In recent years, concerns about liability have played an increasing role in shaping the manner in which health care is provided. While awareness of legal responsibilities is important, fear of criminal and civil liability often distorts the decision-making process—it promotes legal considerations rather than the patient’s wishes and interests as the focus of the decision.

Extending protection from liability to health care professionals in appropriate cases, while beneficial to those professionals, is also important for patients. It is essential to make the patient’s needs the primary consideration in treatment decisions. Moreover, it is unfair to force physicians and other health care professionals to choose, as they now must in some cases, between appropriate medical treatment for their patients and the risk of civil or criminal liability.

The Task Force believes that health care providers who honor an agent’s decisions in good faith should be protected from criminal sanctions, civil liability and professional penalties. However, the immunity extended should only cover claims based on the professional’s good faith reliance on an agent’s decision. Physicians should be obligated to obtain informed consent from an agent, as they would from a patient. Moreover, all health care professionals should remain obligated to provide medical treatment in accordance with applicable standards of care.

***Recommendation***— The physician should provide the agent with medical information necessary to make an informed decision on the patient’s behalf. Once the agent has made a decision, the physician should honor that decision to the same extent as if it had been made by the patient, unless the agent’s authority is restricted in the patient’s proxy. However, the physician should serve as a check and balance to the agent’s exercise of authority in those situations where the physician believes the agent is ill-informed, incapable of serving, or acting in bad faith.

The Task Force also recommends that health care providers should be protected from civil and criminal liability for honoring, in good faith, decisions by health care agents.

See Proposed Legislation, Sections 3.3, 5.2 and 7.1.

## Footnotes

1. For further discussion of the physician's role in "screening out" abusive or ill-founded surrogate decisions, see President's Commission, *Deciding to Forego Life-Sustaining Treatment*, p. 153; Stephen A. Newman, "Treatment Refusals for the Critically and Terminally III: Proposed Rules for the Family, the Physician, and the State," 3 *N.Y. Law Sch. Human Rights Ann.* 35, 71-72 (1985).
2. See President's Commission, *Making Health Care Decisions*, p. 172.
3. The tragic consequences that can follow if a physician overlooks this obligation are poignantly described by Englebert Schucking in "Death at a New York Hospital," *Law, Med. & Health Care*, Vol. 13, No. 6, Dec. 1985, pp. 261-68.





## **VIII. Health Care Proxies in the Long-Term Care and Mental Health Settings**

The far-reaching power delegated by the creation of a health care proxy raises a host of special concerns and dilemmas for residents of long-term care and mental health facilities. For several reasons, these persons may be especially vulnerable to potential abuses associated with the appointment of a health care agent.

A process for the creation and use of a health care proxy should therefore be tailored to respond to their particular needs and concerns. Chief among these concerns is the need to preserve the right to make health care decisions for persons capable of exercising that right, while ensuring that a health care agent is appointed on a voluntary and informed basis under circumstances that promote the patient's interests.

### **Long-Term Care Residents**

Close to 100,000 persons in New York State reside in long-term care facilities, generally referred to as nursing homes. Approximately 75% of long-term care residents are in "skilled nursing facilities," which care for persons with chronic disabilities.<sup>1</sup> The remaining 25% are in "health related facilities," which care for persons with less serious health care needs.<sup>2</sup> The average age of nursing home residents in New York State is eighty-three years old.<sup>1</sup>

The special vulnerability of the institutionalized elderly is due, in part, to the circumstances of institutional living. Admission to any health care facility inevitably involves a substantial loss of privacy and autonomy. Patients in acute care hospitals, for example, no longer make such routine decisions as when to arise, when to eat, and what to wear. These losses are compounded in long-term care facilities, where the constraints of group living impose even greater limitations on personal independence. Equally important, the loss of privacy and control is permanent, and often results, over time, in increasing passivity and an actual decline in decision-making ability.<sup>4</sup>

The near total dependence of residents upon the institution and its employees contributes to this problem. Nursing home placement is often the last resort for persons whose physical and/or mental functioning have become so impaired that they are no longer able to care for themselves. In addition, although most persons enter long-term

care facilities with the assistance of caring relatives and friends, this support usually diminishes as significant others withdraw or as residents outlive those close to them.

In long-term care facilities, the physician-patient relationship differs from the relationship between physician and patient in most acute care settings. Unfortunately, this difference lessens the resident's involvement with and control over health care concerns. For example, residents of long-term care facilities usually have only limited contact with their physician and often do not select their own physician. Consequently, the kind of partnership between physician and patient needed to educate residents about treatment alternatives and empower them to exercise their autonomy in health care matters is only rarely achieved.\* Nurses who care for residents on a day-to-day basis and social workers are often an important source of information and support but cannot give the same range of medical guidance.

Furthermore, many nursing home residents suffer some degree of diminished intellectual functioning that limits their ability to understand the nature of their medical condition and the available treatment alternatives. In separate surveys of nursing homes in the State conducted by the Task Force and by the New York State Health Facilities Association, the respondents estimated that nearly 50% of the residents of long-term facilities lack capacity to make any health care decisions, and approximately 25% of the residents lack capacity to make some decisions.<sup>6</sup> In 1977, the National Center for Health Statistics reported that one-fifth of nursing home residents nationwide had a primary diagnosis of mental disorder or senility.<sup>7</sup> Unfortunately, the autonomy of residents who are fully capable of making treatment decisions may frequently be undermined by the assumption that all elderly persons, and especially the institutionalized elderly, are cognitively impaired and lack decision-making capacity.<sup>8</sup>

### **The Need for Education**

Most nursing home residents have made autonomous decisions throughout their lives and should be empowered to continue to exercise their right to self-determination in important decisions at the end of life. Also, as studies have demonstrated, when the opportunities to make decisions are enhanced, the intellectual decline associated with long-term institutional living can be minimized.<sup>9</sup>

The Task Force believes that long-term care facilities should educate residents about the nature of treatment choices at the end of life and the tools available to implement those choices, including the health care proxy and living will. These efforts should be undertaken shortly after residents are admitted, when

they have had an opportunity to reflect upon their health care goals.

### **Creating the Proxy**

It is important to ensure that residents of long-term care facilities who create health care proxies do so knowingly and voluntarily. Creation of a proxy serves the interests of the institution as well as the resident by facilitating the process of obtaining informed consent. The value to the institution of a surrogate decision-maker, coupled with the dependency of nursing home residents upon their health care providers, creates a situation in which institutional needs or convenience may overwhelm the interests of residents.

When a resident in a long-term care facility creates a health care proxy, one or more persons not affiliated with the facility in which the person resides should be involved. The participation of a disinterested party should be designed to insure that nursing home residents fully comprehend the significance of the document and its implications for future care. Members of organizations that advocate on behalf of the institutionalized elderly, or other respected members of the community, might be called upon to perform this role.

In addition, information about the process by which the proxy was created should be noted in the resident's medical or nursing chart. Routine retrospective review of the proxies created in long-term care facilities could also provide additional protections.

Procedures for creation of the proxy in long-term care facilities should be established by regulation rather than legislation to permit an opportunity for evaluation and the flexibility to change the procedures. Accordingly, the Task Force recommends that the Department of Health should be charged to develop regulations for long-term care facilities regarding the education of residents about health care proxies and other advance directives, procedures for creation of a proxy, and a process for retrospective review of the proxies created in the facility.

### **Determining Capacity**

A determination that a person lacks decision-making capacity does not require a psychiatric or other specialized assessment for most

persons. The determination usually involves a basic assessment of the person's ability to comprehend his or her present situation and the factors involved in a treatment decision. While physicians often seek psychiatric consultation in difficult cases, this consultation is unnecessary in most routine situations.

The determination of capacity for elderly persons in the long-term care setting is often complex. Many nursing home residents have fluctuating capacity or capacity to make some, but not all, health care decisions.<sup>10</sup> In most cases, a psychiatrist or other specialist will not be required to assess the capacity of a nursing home resident. The Task Force proposes, however, that when a resident is determined to lack capacity as a result of mental illness, the physician who conducts the evaluation must either have, or consult with someone who has, specialized training or experience in diagnosing or treating similar conditions.

The Task Force believes that for purposes of its legislative proposal the term “mental illness” should be defined as set forth in Section 1.03 of the Mental Hygiene Law.

An affliction with a mental disease or mental condition which is manifested by a disorder or disturbance in behavior, feeling, thinking or judgment to such an extent that the person afflicted requires care, treatment, and rehabilitation.

Alzheimer’s disease and other neurologic disorders would be included under this broad definition.

The Task Force also believes that the special responsibilities and role of nurses and social workers in long-term care settings should be reflected in the process to determine residents’ capacity to make treatment decisions. Long-term care residents generally have far more contact with nurses and social workers than they do with physicians. Nurses care for residents on a day-to-day basis and are familiar with their habits, needs and personal inclinations.” The Task Force therefore recommends that the determination of a resident’s capacity to make health care decisions for the purpose of triggering the agent’s authority should involve at least one health care professional in addition to the primary physician. The second professional should be someone who has close and frequent contact with the resident, such as a nurse or social worker.

**Recommendations**—Long-term care facilities should educate residents about treatment choices at the end of life and the tools available to implement those choices, including the health care proxy and living will. They should also establish procedures to ensure that residents who create health care proxies do so voluntarily, with an understanding of the scope of authority that may be delegated, the benefits and risks of creating a proxy, and the opportunity to provide specific instructions to the agent.

The determination of capacity of residents in long-term care facilities, when done for the purpose of empowering a health care agent, should involve a physician and a nurse, social worker, or other health care professional who has had close contact with the resident.

See Proposed Legislation, Sections 2.3 and 11.

## **The Mentally Disabled**

Persons with mental disabilities fall into two broad classes: those with mental illnesses and those with developmental disabilities. Each year, more than 500,000 persons receive treatment for mental illness from one or more of the 2,073 licensed facilities in New York State.<sup>12</sup> Residential treatment for mental illness is provided in a range of settings: state-operated psychiatric centers, private psychiatric hospitals, psychiatric units in general hospitals, community residences, family care homes, residential care centers, and special facilities for children. Approximately 25% of the persons treated for mental illness in the State are cared for in one of these residential facilities.

Persons treated for mental illness vary greatly in terms of the nature and duration of their disabilities, the extent of their functional impairment, and their responsiveness to treatment. Although some mentally ill persons are unable to function in daily life, others support themselves financially and live on their own or with their families.

Over 52,000 New Yorkers receive treatment for developmental disabilities, a term used to refer to a broad range of chronic conditions that arise prenatally or in childhood and that substantially impair an individual's intellectual functioning or adaptive behavior.<sup>13</sup> Conditions commonly identified as developmental disabilities include autism, cerebral palsy, epilepsy, mental retardation and muscular dystrophy.

The most profoundly impaired developmentally disabled persons usually reside in state-operated facilities that provide total care. Persons with the mildest impairments often live independently or with their families. Some reside in group homes. Altogether, about 28,000 developmentally disabled persons live in developmental centers, community residences, intermediate care facilities, and family care residences under the auspices of the New York State Office of Mental Retardation and Developmental Disabilities.<sup>14</sup>

The fact that an individual has a mental illness or developmental disability does not in itself establish that the individual lacks capacity to make health care decisions. In many cases, a mental disability

affects some mental abilities without undermining others.<sup>15</sup>

For example, persons who are schizophrenic or have other serious mental disorders may be fully capable of making some or all health care decisions.<sup>18</sup>

Consistent with this clinical reality, New York State courts have upheld the right of persons in mental health facilities to make treatment decisions unless the person has been determined to lack capacity by a judicial finding. Most recently, under the 1986 *Rivers v. Katz* decision, the New York Court of Appeals upheld the right of residents of mental health facilities to refuse antipsychotic medication unless a judicial determination has been made that the resident lacks decision-making capacity.<sup>17</sup>

The Task Force believes that the right to appoint a health care agent, and the opportunity it offers individuals to control fundamental decisions about their lives, should be extended to those mentally disabled persons capable of exercising that right. However, measures must be taken to insure that those who are capable of creating a proxy are assisted in doing so and that those who are incapable are protected from the consequences of their own actions. These measures should relate primarily to four areas: (i) creation of the proxy; (ii) the persons who may serve as agent; (iii) the determination of incapacity that triggers commencement of the agent's authority; and (iv) guidance concerning the treatment decisions of particular relevance to the mentally disabled.

### **Creating the Proxy**

Steps must be taken in mental health facilities to educate residents about the health care proxy and to prevent abuse and an inadequate decision-making process in creation of the proxy. As in the long-term care setting, residents of mental health facilities should be informed and educated about the availability of the health care proxy. Guidance should be offered about how the proxy is created, the nature of the authority delegated and how residents may best use it to pursue their health care goals.

Procedures must also be developed to make certain that residents who create a health care proxy do so voluntarily and have the capacity and information necessary to make an informed choice. For each proxy created, a mechanism must be established to document information about the circumstances under which the proxy was created. Moreover, the use of health care proxies should be monitored on a facility-wide basis to identify any patterns that would suggest abuse or inadequate supervision of the process to create the proxy. These measures should involve persons from outside the institution, either

from the appropriate regulatory authority or from an entity such as Mental Hygiene Legal Service, an organization that provides free legal assistance and advocacy for the mentally disabled in New York State.

The Task Force recommends that specific guidelines for these procedures at mental health facilities should be embodied in regulations developed by the executive agencies with oversight responsibilities for those institutions. Establishment of the procedures in regulations will permit the flexibility needed to tailor the procedures to the needs of the patient populations in diverse mental health facilities across the State.

### **Selecting the Agent**

While some residents of mental health facilities have close family ties, others, especially long-term residents, may have been abandoned by or lost contact with family members. In such cases, residents may be closest to the persons with whom they relate on a daily basis—the health care professionals responsible for their care at the facility. As in the acute care and nursing home contexts, appointment of these persons as agents under a health care proxy raises serious concern about potential conflicts of interest that might undermine the agent's responsiveness and dedication to the resident. However, in the context of mental health facilities, the existence of an effective, independent agency, Mental Hygiene Legal Service, available to represent residents mitigates this concern. The Task Force therefore recommends that when a resident of a mental health facility appoints an employee of the facility as agent under a health care proxy, Mental Hygiene Legal Service should be informed of the appointment and take whatever action it deems appropriate before the employee-agent is granted authority under the proxy.

### **Determining Capacity**

Unlike the determination of decision-making capacity for the general patient population, the assessment of capacity for persons with a mental illness or developmental disability requires specialized expertise and training. Persons without the necessary expertise may err in two directions. They may presume that persons are incapable because of their disability or, conversely, may not appreciate the limitations of patients who appear lucid and capable.

The Task Force proposes that the determination of capacity for mentally disabled persons should be made by, or in consultation with, a health care professional with training or expertise in treating or diagnosing persons with the same or similar disability. This require-

ment should apply to residents in mental health facilities as well as to those who have been transferred to acute care centers.

For persons determined to lack capacity based on mental illness, a psychiatric opinion will often be necessary. For the developmentally disabled, the determination of capacity should be made by a psychiatrist or a psychologist who has training or treatment experience with persons who have the same or similar disability as the patient.

### **Special Treatment Decisions**

Certain treatments such as antipsychotic medication, electro-convulsive shock treatment and psychosurgery have particular relevance for the mentally disabled. Many mentally disabled persons have strong feelings about these treatments. Moreover, surrogate decisions with respect to these treatments have led to abuses in the past.<sup>18</sup> Mentally disabled persons should, therefore, be informed about the scope of the agent's potential authority in relation to these treatments. Specifically, they should be told that their health care agent will have authority to make these treatment decisions unless they limit that authority in the proxy.

Mentally disabled persons should also be encouraged to provide instructions about these treatments in the proxy rather than simply to restrict the agent's authority. If the agent's authority is restricted and instructions about the treatment are not included in the proxy, someone else, perhaps a judge or someone else unknown to the person, will have to make a judgment on the person's behalf when the person loses decision-making capacity. The Task Force therefore recommends that the treatments listed above should be highlighted on the proxy form to encourage people to reflect about and express their wishes about these treatments.

**Recommendation**—Mental health facilities, like long-term care facilities, should devise procedures to educate residents about the health care proxy and to ensure that those who create proxies do so knowingly and voluntarily. The Commissioners of Mental Health and Mental Retardation and Developmental Disabilities should establish the requirements for such procedures in regulations.

An employee of a mental health facility should be permitted to act as agent for a resident provided notice is given to a responsible oversight entity, such as the Mental Hygiene Legal Service. Finally, the determination of capacity of a person with a mental disability should be made by a physician or psychologist with specialized training or experience in diagnosing or treating persons with similar mental disabilities.

See Proposed Legislation, Sections 2.3, 4 and 11.



## Footnotes

1. Long Term Care Services, Office of Health Systems Management, New York State Department of Health.
2. *Id.*
3. Derived from data supplied by Computer Systems Management & Data Processing Group, New York State Department of Health.
4. The syndrome is sometimes referred to as "learned helplessness." It is characterized by passivity, hopelessness and intellectual slowness, resulting from ongoing situations over which the individual has no control. Ian Robertson, "Learned Helplessness," *Nursing Times*, Vol. 17, No. 24, Dec. 1986, pp. 28-30. This phenomenon has been experimentally demonstrated in the institutionalized elderly in several classic studies. See Jerry Avorn and Ellen Langer, "Induced Disability in Nursing Home Patients: A Controlled Trial," *J.Am.Ger. Soc.*, Vol. 30, June 1982, pp. 397-400; Judith Rodin and Ellen Langer, "The Effects of Choice and Enhanced Personal Responsibility for the Aged: A Field Experiment in an Institutional Setting," *J.Pers. & Soc. Psych.*, Vol. 34, No. 2, Aug. 1976, pp. 191-98; Richard Schulz, "Effects of Control and Predictability on the Physical and Psychological Well-Being of the Institutionalized Aged," *J.Pers. & Soc.Psych.*, Vol. 33, No. 5, May 1976, pp. 563-73; Richard Schulz and Barbara Hanusa, "Long-Term Effects of Control and Predictability—Enhancing Interventions: Findings and Ethical Issues," *J.Pers. & Soc.Psych.*, Vol. 36, No. 11, Nov. 1978, pp. 1194-1201.
5. Several other factors also contribute to this problem. First, physicians generally see nursing home residents at intervals determined by state and federal regulation. David Rabin, "Physician Care in Nursing Homes," *Ann.Int.Med.*, Vol. 94, No. 1, Jan. 1981, pp. 126-28. Under New York State regulations, a nursing home patient may be seen by a physician as infrequently as every sixty days. 10 NYCRR §§ 415.1(d) 415.5(b) 416.1(g),(h). In addition, research shows that physicians generally do not communicate as well with older patients as they do with younger ones. One study showed that physicians tend to ask fewer questions and provide less information and support to elderly patients. Michele Greene, Ronald Adelman and Rita Charon, "Ageism in the Medical Encounter," *Language and Communication*, Vol. 6, No. 1-2, 1986, pp. 113-24. This difference is of particular concern in light of recent research suggesting that radical or high risk treatments are more commonly recommended for patients who are physically handicapped, socially isolated, and lacking motivation. See James Till, "Quality of Life Assessment; Beware the Tyranny of the

Majority,” *Humane Medicine*, Vol. 2, No. 2, Nov. 1986, pp. 100-104.

6. The 175 responses to the Task Force Survey of long-term care facilities in New York State, when averaged, reveal that 47% of the long-term care residents lack capacity to make *any* health care decisions, 26% have capacity to make *some* health care decisions, and 26% have capacity to make *all* health care decisions. See Appendix 2, Table C-1, p. 172. These findings are similar to those obtained in a survey by the New York State Health Facilities Association (NYSHF). The responses of 74 NYSHF members, when averaged, indicate that 52% of the residents lack capacity to make any health care decisions, 27% have capacity to make some health care decisions, and 21% have full decision-making capacity. New York State Health Facilities Association, “Survey Response on Health Care Decision Making,” unpublished memorandum, November 26, 1986.

7. Senate Special Committee on Aging, *Aging America: Trends and Projections*, 1985-86 edition, p. 91.

8. Muriel Ryden, “Environmental Support for Autonomy in the Institutionalized Elderly,” *Res.Nurs. & Health*, Vol. 8, 1985, pp. 363-71.

9. See n.4.

10. See n. 6.

11. In “The Nurse as Advocate: A Philosophical Foundation for Nursing,” Leah L. Curten describes the role of nurses who, caring for patients for sustained periods of time, develop a special intimacy and appreciation of patients, from a more holistic perspective. *Adv.Nurs.Sci.*, Vol. 1, No. 3, April 1979, pp. 1-10. Nicholas Rango also stresses the special value of the nurses’ observations. “The Nursing Home Resident with Dementia: Clinical Care, Ethics, and Policy Implications,” *Ann.Int.Med.*, Vol. 102, No. 6, June 1985, pp. 835-41.

12. Office of Mental Health, 1985 Annual Report, p. 24.

13. Office of Mental Retardation and Developmental Disabilities, *Strengthening the Continuum 1987-1990* (1987), pp. 22-36.

14. Office of Mental Retardation and Developmental Disabilities, *Pathways to the Future: Critical Steps for 1986*, p. 7.

15. See generally, American Psychiatric Association, *Diagnostic and Statistical Manual*, 3rd edition, (1980). See also, Brooks, “Constitutional Right to Refuse Antipsychotic Medications,” 8 *Bull.Am.Acad. Psychiatry & Law* 179, 191 (1980); Charles Culver, Richard Ferrell, and Ronald Green, “ECT and Special Problems of Informed Consent,” *Am.J.Psychiatry*, Vol. 137, No. 5, May 1980, p. 586.

16. Mary Mahowald and Virginia Abernathy, "When a Mentally Ill Woman Refuses Abortion," *Hastings Ctr.Rpt.*, Vol. 15, No. 2, April 1985, p. 23; Alan Stone, "Informed Consent: Special Problems for Psychiatry," *Hosp. & Commun. Psychiatry*, Vol. 30, No. 5, May 1979, p. 326.; Stanley Reiser, "Refusing Treatment for Mental Illness: Historical and Ethical Dimensions," *Am.J.Psychiatry*, Vol. 137, No. 3, March 1980, p. 331.
17. *Rivers v. Katz*, 67 N.Y.2d 363, 438 N.Y.S.2d 266, 420 N.E.2d 63, *cert. denied*, 454 U.S. 858 (1981).
18. See Plotkin, "Limiting the Therapeutic Ory: Mental Patient's Right to Refuse Treatment," 72 *N.W.U.L. Rev.* 461; Philip Reilly, "Eugenic Sterilization in the United States," *Genetics and the Law III*, Aubrey Milunsky and George Annas (eds.) (New York: Plenum Press, 1985), pp. 227-241.



## **IX. Making the Proxy Work— The Need for Public Education**

The enactment of health care proxy legislation will provide a new and effective vehicle for citizens of New York State to exercise their right to make treatment decisions. That opportunity, however, will only be as meaningful as public awareness of the law and the options it creates. For this reason, the Task Force believes that a vigorous and widespread educational campaign is an essential component of its health care proxy proposal. It therefore strongly recommends that the Commissioner of Health be charged with the responsibility of implementing and coordinating a campaign to inform the public about the health care proxy. The campaign should employ all effective and appropriate channels of communication including the mass media and coordinated efforts with health care facilities, patient advocacy groups and community organizations. The resources necessary to perform this function should be appropriated as part of the health care proxy legislation.

The educational effort should seek to achieve several goals. First, it should publicize the right to create a health care proxy and provide basic information about how that right can be exercised. Equally important, use of a health care proxy should be encouraged. The proxy will enable people to exercise some control over intensely personal health care decisions that may have to be made on their behalf. It is an invaluable tool not just for the elderly or those who are ill, but for all members of society.

Intensive efforts should also be undertaken to educate health care professionals—physicians, nurses, social workers, and health care administrators. These professionals will often be the persons who make the proxy forms available and to whom patients will turn for assistance in creating the proxy. They also must respond to the proxies and implement the policies embodied in the legislation. It is therefore essential that health care professionals understand the principles and procedures governing the proxy's use and its legal significance.



## **X. Conclusion**

The Task Force’s legislative proposal on the health care proxy affirms and protects a right long-recognized in our society—the right to make choices about one’s own body, and specifically, the right to consent to or refuse treatment. Few rights are more intensely personal or deeply cherished.

Forty states and the District of Columbia now have legislation designed to acknowledge and protect the individual’s right to make choices about his or her own dying process. Protection for this fundamental right should also be granted to the people of New York State. Such protection is long overdue and urgently needed.

The health care proxy has been widely recognized as the best vehicle to provide this protection and extend the individual’s participation in health care decisions beyond the loss of decision-making capacity. It can be used to delegate authority for consent to treatment as well as authority to forego life-sustaining measures. It will provide a powerful, effective new tool for persons to ensure that their wishes about treatment will be honored even when they can no longer speak for themselves.

The movement for “death with dignity” reflects the strong conviction that technological advances must not become ends in themselves, removed from the desires and condition of the patients they were designed to serve. Instead, respect for the dignity of all persons and recognition of the limitations of our medical advances requires that people be allowed to participate in decisions about their own dying process. Only in this manner can we ensure that technological possibilities do not become imperatives and that we protect the strongly held beliefs and wishes of those who are most ill and most vulnerable among us.





## Minority Report

**John A. Alesandro Mario**  
**L. Baeza Richard J.**  
**Concannon John J. Regan**  
**Betty Bone Schiess**

Put simply, the position of the Task Force members subscribing to this minority report is that the proposed legislation should give the public the option of choosing to execute either an immediate proxy or a springing proxy, not just the latter as the majority recommends. This minority report is confined to that single issue; it is not meant to suggest disagreement with other recommendations of the Task Force report and proposed legislation.

By an immediate proxy, we mean not only that the appointment of the proxy should take effect at the time the proxy is executed by the patient, but also that the patient with capacity must continue to be involved in the process of making decisions for his or her own health care to the extent that he or she desires such involvement. Specifically, by “immediate” proxy we mean one essentially in the form set forth in the Appendix to this Minority Report.

We do not believe that anyone should support, let alone sign, a health care proxy that could permit an agent to consent to the imposition or withholding of treatment of a person with capacity without an opportunity for that person’s meaningful involvement in the decision-making process. Thus, while we do not object to the use of the threefold distinction in the Majority Report (“immediate,” “consultation,” and “springing”), realistically there are only two kinds of proxy that should be, or indeed were during the discussions of the Task Force, seriously considered: an immediate proxy that includes reasonable involvement of the patient with capacity, and a springing proxy that requires a legitimate determination of incapacity before the individual chosen by the patient to be agent has any authority to become involved on the patient’s behalf.

Indeed, we feel that many concerns raised about immediate proxies largely relate to proxies that might be able to be used in some way to avoid or circumvent the involvement of a capable patient in the health care decision-making process. We would oppose adoption of any statute that does not clearly require the physician to seek first the informed consent of a patient with capacity before the agent’s authority can be exercised.

Why should the proposed legislation authorize both immediate and springing proxies? This option better promotes and enhances patient autonomy. All persons, not solely the incapacitated, should be permitted to exercise through an agent their right of privacy and their right to give informed consent to treatment. Limiting the power of an agent to situations where the patient is incapacitated deprives the patient with capacity of a significant aspect of his or her autonomy.

As a practical matter, the kind of immediate proxy we are recommending would be especially helpful to frail patients who, while still possessing capacity, may be too debilitated to participate meaningfully in any decision-making process. Having appointed an agent of their choice in an immediate proxy, they would have the option of referring their attending physician to that proxy to obtain the required informed consent. There will be no need for a determination of incapacity before the agent can act nor any question of the agent's authority to act. Nor would this process interfere with the customary relationship between physician and patient and the dialogue that normally occurs between them, except to the extent that the patient directs that the agent play a role in the process.

By contrast, a springing proxy may leave this debilitated patient who has capacity without adequate protection. The agent has no authority to act because the patient still has capacity. However, the patient may lack the physical ability and energy to participate meaningfully in the decision-making process. In this vacuum, the physician may turn for guidance to relatives or friends who are not necessarily the patient's chosen spokespersons. Or the physician himself or herself may make the decision with only token consent or, even worse, lack of objection from the patient. In our view, that leaves too much power and discretion over treatment decisions in the hands of physicians.

Under the same circumstances, an immediate power would allow a patient to refer the physician to the patient's agent with assurance on everyone's part that meaningful discussion and decision-making will take place with someone chosen in advance by the patient. The agent could act confident of authority, and his or her decision should be relied on by the physician with equal confidence. In addition, later questions about the capacity of the patient or the authority of the agent, which might arise under a springing proxy, are avoided. Most importantly, the patient's advance decision as to how and by whom he or she wanted things done, will have been carried out.

The springing proxy also may not be adequate in the case of the patient whose capacity may fluctuate, hardly an uncommon occurrence. The agent's authority would similarly fluctuate, coming into existence and disappearing, creating a rather bizarre situation. The immediate power with the durability of the proxy provides the means for a more sensible resolution of that problem. The agent always has authority provided the patient has directed the physician to the agent, and yet the patient is still informed about treatment and always has the opportunity to change or challenge any decision.

The immediate proxy solves another problem that the springing proxy cannot avoid. Many people view with distaste the need for a determination of their incapacity as a condition for an agent to act on their behalf. Indeed, if they realize that the only way their agent can act on their behalf is for them to be subjected to such a determination, they may very well dismiss the whole idea.

One should note as a safeguard against abuse of an immediate proxy the proper role of the agent as specified in the proposed legislation. Section 3, paragraph 1, permits the principal to include express limitations on the agent's authority in the health care proxy itself. More important, Section 3, paragraph 2, obliges the agent to make health care decisions first in accord with the agent's assessment of the patient's wishes and, only if the patient's wishes are unknown, in accord with the agent's assessment of the patient's best interests. Certainly, with an immediate proxy, the patient with capacity who directs the physician to receive informed consent from an agent will at the same time have the opportunity to express his or her wishes about treatment to the agent, and the latter will be obliged to make health care decisions in accord with those wishes.

The historical development of the power of attorney for property matters provides a useful perspective on the use of the immediate proxy for health care decisions. Initially, the law authorized an immediate power over property that terminated upon the incompetence of the grantor of the power because it was felt that, when incompetent, the grantor lacked the ability to revoke and that no power should be irrevocable. With further experience and out of the desire to allow people to provide for control over their affairs after they become incompetent, the law created the durable power of attorney that survived incapacity. Finally optional springing powers triggered by incompetency became part of the law of many but not all states. In thus expanding the grantor's options, current law has not abandoned the immediate power. Instead, it has chosen to prevent

possible confusion or mischief by providing safeguards against unintentional creation of proxies, such as adopting specific statutory forms with heightened notices to the possibly unwary or unsophisticated of the nature of the document being signed. The minority proposal, by providing for both immediate and springing proxies, takes the same approach.

Interestingly, the situation in which a health care proxy is exercised is strikingly different from the usual proxy for property matters. In the latter case, the grantor of a power is seldom present when an agent acts on his or her behalf. By contrast, the patient creating a health care proxy is always present and involved whenever the proxy may be called upon to act. Thus the patient with capacity will always be in a position to protect his or her own interests at the time a treatment decision is made.

One can debate the differences between one's body and one's property and the extent to which those differences should affect delegations of authority over decisions regarding each of them, but abstractions should not override specific recommendations for allowing individuals to make their own decisions regarding delegation. We believe that the right to choose is accomplished through provision of an individual's option to decide between an immediate or a springing proxy.

A decision to submit a minority report is a difficult one. The issues are complex and there is merit to achieving Task Force consensus on recommendations. Nevertheless, there are occasions when it is necessary to question a recommendation, and a number of Task Force members feel that depriving the public of the right to choose between an immediate proxy and a springing proxy is one of those occasions.

## Appendix to Minority Report

The following provisions, if inserted into the proposed health care proxy legislation, would permit the principal to choose between giving an agent authority that commences immediately and authority that “springs” into effect upon a determination that the principal lacks capacity:

### **§ 2. Appointment of Health Care Agent; Health Care Proxy.**

4. ***Commencement of agent’s authority.*** An adult may specify whether the agent’s authority shall commence (a) upon execution of the health care proxy, or (b) upon a determination, pursuant to section 4 of this article, that the principal lacks capacity to make health care decisions. In the absence of an express provision in the proxy, the authority shall become effective upon execution of the proxy.

5. ***Decision on behalf of principal with capacity.*** Notwithstanding the existence of a proxy making an agent’s authority effective upon execution, as long as a principal has capacity to make health care decisions, a health care provider shall first seek to obtain a health care decision from the principal, in the manner appropriate for obtaining a decision in the absence of the proxy. If the principal expresses to the provider, by words or otherwise, a desire for the agent to make the decision, the provider shall:

- (a) seek to obtain such decision from the agent;
- (b) after obtaining a decision from the agent, explain to the principal the nature of the agent’s decision; and
- (c) record the circumstances of obtaining the decision in the principal’s medical record.



## Minority Report

### J. David Bleich

I fully concur in the recommendation that competent patients be accorded the opportunity to designate an agent for purposes of making health-care decisions — so long as the proxy is designed to be exercised for the purpose of achieving a therapeutic result.

The major concern, to which allusion is indeed made in the Minority Report, cannot be sufficiently emphasized. Experience testifies that, in actuality, in far too many instances, competent patients do not make crucial decisions affecting their own care. Age, frailty, language barriers, lack of medical sophistication, bewilderment, lethargy and depression, singly or in combination, serve to create a situation in which the patient abdicates, or appears to abdicate, decision-making responsibilities. Alternatively, the identical factors create a situation in which securing the patient's consent entails more time and/or effort than the physician feels he should be required to expend in such an endeavor. The moral dilemma faced by an overburdened and harried physician who knows that the time and effort expended in securing meaningful consent may well compromise the care he must render to other patients should not be lightly dismissed.

The result is an untold number of cases in which *de facto* consent is obtained from family members despite their present lack of legal authority to make such decisions on behalf of the patient. The person from whom consent is obtained is not necessarily the person to whom the patient, were he consulted, would wish to delegate such authority. And when family members disagree, the dilemma is only compounded. Of even greater concern is the fact that, quite frequently, it is the physician himself who becomes the decision-maker. Often the physician acts in this capacity for the noblest of reasons. Yet the Task Force feels strongly that a physician responsible for the care of a patient should never serve in the role of proxy in making decisions on behalf of that patient. The reasons for this recommendation are entirely cogent and need not be reiterated. The selfsame considerations which serve to bar a physician from acting as the designated proxy of an incompetent patient serve *a fortiori* to support a recommendation that a physician be prevented from serving as the undesignated proxy of a competent patient.

I must, however, add one caveat: designation of a proxy by a competent patient is justified only for delegation of authority for the purpose of weighing the pros and cons of alternatively available therapies or weighing the risk-benefit factors inherent in a proposed treatment. Such decisions are predicted upon one prior assumption: the desired goal is cure or, *de minimis*, maximum prolongation of life. The decision itself is simply with regard to the means of achieving that end. Decisions for the withholding of potentially life-prolonging treatment are based upon an entirely different premise: they are designed to result in the patient's early demise.

Even in the extremely limited circumstances under which some ethicist might regard such a decision to be morally justified, in the case of a competent patient, it would be thoroughly unconscionable to sanction such a course of action without the patient's own fully informed consent. A decision to die without the patient's own fully informed consent. A decision to die is far too awesome a matter to be delegated to a proxy.



# Appendix A

## Health Care Proxy Proposed Legislation

### Section

1. Definitions.
2. Appointment of Health Care Agent; Health Care Proxy.
3. Rights and Duties of Agent.
4. Determination of Lack of Capacity to Make Health Care Decisions for the Purpose of Empowering Agent.
5. Provider's Obligation.
6. Revocation.
7. Immunity.
8. Liability for Health Care Costs.
9. Requiring or Prohibiting Execution of a Health Care Proxy.
10. Proxies Executed in Other States.
11. Creation and Use of Proxies in Residential Health Care And Mental Hygiene Facilities.
12. Regulations.
13. Rights to be Publicized.

### § 1. Definitions.

1. *"Attending physician"* means the physician, selected by or assigned to a patient, who has primary responsibility for the treatment and care of the patient.
2. *"Capacity to make health care decisions"* means the ability to understand and appreciate the nature and consequences of health care decisions, including the benefits and risks of and alternatives to any proposed health care, and to reach an informed decision.
3. *"Health care"* means any treatment, service or procedure to diagnose or treat an individual's physical or mental condition.
4. *"Health care agent"* or *"agent"* means an adult to whom authority to make health care decisions is delegated under a health care proxy.

5. ***"Health care provider"*** means an individual or facility licensed, certified, or otherwise authorized or permitted by law to administer health care in the ordinary course of business or professional practice.
6. ***"Health care proxy"*** means a document delegating to an agent the authority to make health care decisions, executed in accordance with the requirements of this article.
7. ***"Hospital"*** means a hospital and a residential health care facility as defined in section 2801 of the Public Health Law, and a mental hygiene facility as defined in paragraph (8) of this section.
8. ***"Mental hygiene facility"*** means a facility operated or licensed by the Office of Mental Health or the Office of Mental Retardation and Developmental Disabilities.
9. ***"Principal"*** means a person who has executed a health care proxy.
10. ***"Residential health care facility"*** means a residential health care facility as defined in section 2801.3 of the Public Health Law.

## **§ 2. Appointment of Health Care Agent; Health Care Proxy.**

1. ***Right to appoint agent; presumption of competence.***
  - (a) A competent adult has the right to appoint a health care agent.
  - (b) For the purpose of this section, every adult shall be presumed competent unless determined otherwise pursuant to court order.
2. ***Health care proxy; execution; witnesses.*** A competent adult may appoint a health care agent by a health care proxy, signed by or at the direction of the adult in the presence of two subscribing adult witnesses. The witnesses shall affirm that the principal appeared to be of sound mind and free from duress. The person appointed as agent shall not act as witness to execution of the health care proxy.
3. ***Restrictions on who may be appointed agent.***
  - (a) An operator, administrator or employee of a hospital may not be appointed as health care agent by any person who, at the time of the appointment, is a patient or resident of, or has applied for admission to, such hospital.

(b) The restriction in paragraph (a) of this subdivision shall not apply to:

(i) an operator, administrator or employee of a mental hygiene facility, provided the person appointed agent gives notice of the appointment to Mental Hygiene Legal Service promptly after learning of the appointment and before acting as agent;

(ii) an operator, administrator or employee of a hospital who is related to the principal by blood, marriage or adoption;

(iii) a physician, subject to the limitation set forth in paragraph (c) of this subdivision.

(c) If a physician is appointed agent, the physician shall not act as the patient's attending physician after the authority under the health care proxy commences, unless the physician declines the appointment as agent at or before such time.

4. ***Commencement of agent's authority.*** The agent's authority shall commence upon a determination, made pursuant to section 4 of this article, that the principal lacks capacity to make health care decisions.

5. ***Contents and form of health care proxy.***

(a) The health care proxy shall:

(i) identify the principal and agent;

(ii) indicate that the principal intends the agent to have authority to make health care decisions on the principal's behalf;

(iii) describe the limitations, if any, that the principal intends to impose upon the agent's authority; and

(iv) indicate that the agent's authority shall become effective if the principal subsequently loses capacity to make health care decisions.

(b) The health care proxy shall be executed in accordance with the requirements of section 2.2 and may, but need not, be in the form set forth in the Appendix to this article.

### **3. Rights and Duties of Agent.**

1. ***Scope of authority.*** Subject to any express limitations in the health care proxy, an agent shall have the authority to make any and all health care decisions on the principal's behalf that the principal could make, including decisions about life-sustaining treatment.
2. ***Decision-making standard.*** After consultation with health care providers, the agent shall make health care decisions: (a) in accordance with the agent's assessment of the principal's wishes, including the principal's religious and moral beliefs, or (b) if the principal's wishes are unknown, in accordance with the agent's assessment of the principal's best interests.
3. ***Right to receive information.*** Notwithstanding any law to the contrary, the agent shall have the right to receive medical information necessary to make informed decisions regarding the principal's health care.
4. ***Priority over other surrogates.*** Health care decisions by an agent on a principal's behalf shall have priority over decisions by any other person, except as otherwise provided in the health care proxy or in section 4.4 of this article.

### **§ 4. Determination of Lack of Capacity to Make Health Care Decisions for the Purpose of Empowering Agent.**

1. ***Determination by attending physician.***
  - (a) A determination that a principal lacks capacity to make health care decisions shall be made by the attending physician to a reasonable degree of medical certainty. The determination shall be stated in writing and shall contain the attending physician's opinion regarding the cause and nature of the principal's incapacity as well as its extent and probable duration.
  - (b) If the attending physician determines that a patient lacks capacity because of mental illness or developmental disability, the attending physician who makes the determination must have, or must consult with a health care professional who has, specialized training or experience in diagnosing or treating mental illnesses or developmental disabilities of the same or similar nature.

(c) A physician who has been appointed as a patient's agent shall not make the determination of the patient's capacity to make health care decisions.

2. ***Notice of determination.*** Notice of a determination that a principal lacks capacity to make health care decisions shall promptly be given: (a) to the principal, orally and in writing, where there is any indication of the principal's ability to comprehend such notice; (b) to the agent; and (c) if the patient is in or is transferred from a mental hygiene facility, to the facility director.

3. ***Limited purpose of determination.*** A determination made pursuant to this section that a principal lacks capacity to make health care decisions is solely for the purpose of empowering an agent to make health care decisions pursuant to a health care proxy.

4. ***Priority of principal's decision.*** Notwithstanding a determination pursuant to this section that the principal lacks capacity to make health care decisions, where a principal objects to a health care decision made by an agent, the principal's decision shall prevail unless the principal is determined to lack capacity to make health care decisions by court order.

5. ***Effect of recovery of capacity.*** In the event the attending physician determines that the principal has regained capacity:

- (a) the authority of the agent shall cease, but shall recommence if the principal subsequently loses capacity; and
- (b) the principal's consent for treatment shall be required.

## **§ 5. Provider's Obligation.**

1. ***Duty to insert proxy in medical record.*** A physician who is provided with a health care proxy shall arrange for the proxy or a copy thereof to be inserted in the principal's medical record.

2. ***Duty to honor agent's decision.*** A health care provider shall comply with health care decisions made by an agent under a health care proxy to the same extent as if such decisions had been made by the principal, subject to any limitations in the health care proxy and to the provisions of section 4.4 of this article.

## **§ 6. Revocation.**

### **1. *Means of revoking proxy.***

- (a) A competent adult may revoke a health care proxy by notifying the agent or a health care provider orally or in writing or by any other act evidencing a specific intent to revoke the proxy.
- (b) For the purpose of this section, every adult shall be presumed competent unless determined otherwise pursuant to court order.
- (c) A health care proxy shall also be revoked upon:
  - (i) execution by the principal of a subsequent health care proxy; or
  - (ii) the divorce or legal separation of the principal and spouse, where the spouse is the principal's agent under a health care proxy.

**2. *Duty to record revocation.*** A physician who is informed of or provided with a revocation of a health care proxy shall immediately: (i) record the revocation in the principal's medical record and (ii) notify the agent and the medical staff responsible for the principal's care of the revocation. Any member of the nursing staff informed of or provided with a revocation of a health care proxy pursuant to this section shall immediately notify a physician of such revocation.

## **§ 7. Immunity.**

- 1. ***Provider immunity.*** No health care provider or employee thereof shall be subjected to criminal or civil liability, or be deemed to have engaged in unprofessional conduct, for carrying out in good faith a health care decision by an agent pursuant to this article.
- 2. ***Agent immunity.*** No person acting as agent pursuant to a health care proxy shall be subjected to criminal or civil liability for making a health care decision in good faith pursuant to this article.

**§ 8. Liability for Health Care Costs.**

Liability for the cost *of* health care provided pursuant to an agent's decision shall be the same as if the health care were provided pursuant to the principal's decision.

**§ 9. Requiring or Prohibiting Execution of Health Care Proxy.**

A person may not require or prohibit the execution of a health care proxy by an individual as a condition for providing health care services or insurance to such individual.

**§ 10. Proxies Executed in Other States.**

Nothing herein shall limit the enforceability of a health care proxy or similar instrument executed in another state or jurisdiction in compliance with the law of that state or jurisdiction.

**§ 11. Creation and Use of Proxies in Residential Health Care and Mental Hygiene Facilities.**

Residential health care facilities and mental hygiene facilities shall establish procedures:

- (a) to provide information to residents about their right to create a health care proxy under this article;
- (b) to educate residents about the authority delegated under a health care proxy and how a proxy is created; and
- (c) to ensure that each resident who creates a proxy while residing at the facility: (i) does so voluntarily; and (ii) understands the health care proxy, including the scope of authority that may be delegated, the benefits and risks of creating the proxy, and the opportunity to provide specific instructions to the agent in the proxy.

Such procedures shall be established in accordance with regulations issued by the Commissioners of Health, Mental Health, and Mental Retardation and Developmental Disabilities for facilities subject to their respective regulatory authorities.

**§ 12. Regulations**

The Commissioner of Health shall establish such regulations as may be necessary for the implementation of this article, subject to section 11 of this article.

**§ 13. Rights to be Publicized**

The Commissioner of Health shall prepare a statement summarizing the rights, duties and requirements of this article and shall require that a copy of such statement (a) is furnished to patients or their families at or prior to the time of admission to a hospital, and to each member of the hospital's staff; and (b) is posted in a public place in each hospital. The statement of rights required by this section may be included in any other statement of patients' rights required by other provisions of the Public Health Law.



## **Appendix to Legislation Health Care Proxy**

### **Information about the Health Care Proxy**

This is an important legal document. Before signing this document, it is vital for you to understand the following facts:

This document gives the person you name as your agent the authority to make any and all health care decisions for you, except to the extent you state otherwise in this document. “Health care” means any treatment, service or procedure to diagnose or treat your physical or mental condition. Your agent therefore can have the power to make a broad range of health care decisions for you, including decisions about withdrawing or withholding life-sustaining treatment.

Your agent’s authority will begin when your physician determines that you lack the capacity to make health care decisions. You will be informed of this determination when it is made and will have an opportunity to object and assert your right to make health care decisions on your own behalf.

You may state in this document any treatment that you do not desire and/or those that you want to make sure you receive. Your agent will be obligated to follow your instructions when making decisions on your behalf.

Examples of medical treatments about which you may wish to give your agent special instructions are:

- |                                                                             |                             |
|-----------------------------------------------------------------------------|-----------------------------|
| • artificial respiration                                                    | • blood transfusions        |
| • artificial nutrition and hydration (nourishment provided by feeding tube) | • abortion                  |
| • cardiopulmonary resuscitation (CPR)                                       | • sterilization             |
| • antibiotics                                                               | • antipsychotic medication  |
| • dialysis                                                                  | • electroconvulsive therapy |
| • transplantation                                                           | • psychosurgery             |
|                                                                             | • other treatments          |

Unless you state otherwise, your agent will have the same authority to make decisions about these treatments as you would have had. This is not, however, a complete list of the treatments about which you may leave instructions. Nor does the list mean that you, and consequently your agent, can legally refuse these treatments under all circumstances.

It is important that you discuss this document with your physician or another health care professional before you sign it to make sure that you understand the nature and range of decisions that may be made on your behalf. You may also wish to give your physician a signed copy. You do not need a lawyer's assistance to complete this document.

The person you appoint as agent must be over eighteen years old. If you appoint a physician as your agent, he or she may have to choose between acting as your agent or as your attending physician; the law does not permit a physician to do both at the same time. Also, if you are a patient or resident of a hospital, nursing home or mental hygiene facility, there are special restrictions on appointing a person who works for that facility as your agent. You should ask the administrator or other personnel at the facility to explain those restrictions.

You should inform the person you appoint that he or she will be your health care agent. You should discuss this document with your agent and give him or her a signed copy. Your agent will not be liable for health care decisions made in good faith on your behalf.

Even after you have signed this document, you have the right to make health care decisions for yourself as long as you are able to do so, and treatment cannot be given to you or stopped over your objection. You have the right to revoke the authority granted to your agent by informing him or her or your health care provider orally or in writing.

#### **Instructions for Completing the Health Care Proxy**

**Item (1):** Insert your name (i.e., the name of person who is appointing a health care agent) and the name, home address and telephone number of the agent.

**Item (2):** If you have special instructions for your agent, you should state them here. Also, if you wish to limit your agent's authority in any way, you should state so here. If you do not state any limitations, your agent will have authority to make any and all health care decisions on your behalf that you could have made, including the authority to consent to or refuse life-sustaining treatment.

**Item (3):** You may, if you wish, insert the name, home address and telephone number of an alternate agent.

**Item (4):** You must date and sign the proxy. If you are unable to sign yourself, you may direct someone else to sign in your presence. Be sure to include your address.

**Item (5):** Two witnesses 18 years of age or older must sign your proxy. The person who is appointed agent cannot act as a witness.

## Health Care Proxy Form

(1) \_\_\_\_\_ I, hereby \_\_\_\_\_ appoint  
\_\_\_\_\_, \_\_\_\_\_  
Name of principal Name of agent  
\_\_\_\_\_ as my  
Home address and telephone number of agent

health care agent to make any and all health care decisions for me, except to the extent I state otherwise in this document.

This health care proxy shall take effect in the event I become unable to make my own health care decisions, as determined by the physician who has primary responsibility for my treatment.

(2) I direct my agent to make health care decisions in accordance with my wishes as stated below or as otherwise known to him or her:

Statement of wishes concerning health care:

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**IMPORTANT:** For examples of medical treatments that you may wish to give your agent instructions about, see "Information about the Health Care Proxy," at the beginning of this form.

(3) In the event the person I appoint above is unable, unwilling or unavailable to act as my health care agent, I hereby appoint

\_\_\_\_\_  
Name of alternate agent

\_\_\_\_\_  
Home address and telephone  
as my health care agent.

(4) \_\_\_\_\_ Signed this \_\_\_\_\_ day \_\_\_\_\_ of \_\_\_\_\_

Signature: ^

Address: ^

(5) I declare that the person who signed or asked another to sign this document is personally known to me, that he or she signed or asked another to sign this document in my presence, and that he or she appears to be of sound mind and under no duress, fraud, or undue influence. I am not the person appointed as agent by this document.

First Witness: \_\_\_\_\_

Address: \_\_\_\_\_

Second Witness: \_\_\_\_\_

Address: \_\_\_\_\_





# Appendix B

## POLICIES ON LIFE-SUSTAINING TREATMENT: SURVEY OF NEW YORK HOSPITALS AND NURSING HOMES

### Introduction

The Task Force on Life and the Law conducted a survey of the hospitals and nursing homes in New York State to obtain information about their policies concerning the withdrawal or withholding of life-sustaining treatment.<sup>2</sup> The survey asked facilities about their policies on living wills, powers of attorney, the determination of patients' decision-making capacity and other issues.

The charts set forth in Tables A through I summarize the responses to selected questions. The responses were obtained from facility spokespersons, primarily administrators, and therefore do not necessarily reflect the practices of individual physicians.

### TABLE A—Profile of Respondents

The Task Force sent questionnaires to 239 members of the New York State Hospital Association, reaching about 89% of the hospitals in the State. A similar questionnaire was sent to 622 nursing homes, nearly every nursing home in the State.

One hundred thirty-nine hospitals and 196 nursing homes completed the questionnaire. Most of the hospital respondents were community hospitals. The respondents were evenly distributed by size and by geographic region.

<sup>1</sup>The Task Force expresses its gratitude to the Hospital Association of New York State and the New York Association of Homes and Services for the Aging for their valuable advice and assistance. The Task Force also thanks Barbara Pace and Julia Skibber for their help in tabulating responses, and Steve Kim, Ph.D., Director of the Computer Systems Management and Data Processing Group, New York State Department of Health, for processing the survey results.

<sup>2</sup> The Task Force did not seek a response from health-related facilities since these

A majority of the nursing home respondents provide only skilled nursing services; a minority provide both skilled nursing services and health-related services.<sup>3</sup> About two-thirds of the nursing home respondents have more than 100 beds. The respondents included significantly more voluntary nursing homes than proprietary homes.

### **TABLE B—Guidelines for Determining Capacity**

The determination of capacity is a critical benchmark for patients in hospitals and nursing homes: it distinguishes those patients who make or participate in treatment decisions from those who need someone else to decide on their behalf. Nevertheless, the questionnaire responses indicate that less than one in three of the hospital respondents and less than one in seven of the nursing home respondents have written guidelines for determining capacity. Thus, it appears that in the vast majority of facilities the determination is made on an ad hoc basis without guidelines to insure that the patient's interests are protected.

Among the hospitals, tertiary facilities, larger hospitals and hospitals affiliated with a medical school are more likely to have written guidelines for determining capacity. The facility's size, sponsorship or affiliation with a hospital did not have a significant impact on responses by nursing homes.

### **TABLE C—Estimate of Patient Capacity Level**

Nursing homes were asked to estimate the percentage of residents who have various levels of decision-making capacity. Information about the extent of diminished capacity among nursing home residents suggests how often treatment decisions must be made on behalf of residents, thereby highlighting the importance of clear guidelines for: (i) determining capacity; (ii) advance decision-making; and (iii) decisions by family members or others on a patient's behalf in the absence of an advance decision.

Responses to the question show that, in the facilities' view, two out of four residents lack capacity to make *any* health care decisions while one out of four lacks the capacity to make some decisions. Thus, a strikingly large number of residents require surrogate decision-making, if they have not previously made their wishes known.

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facilities provide only limited medical treatment and confront issues about life- sustaining treatment less frequently.

Small nursing homes reported a notably lower percent of residents with full capacity, and a corresponding higher percent of residents with no capacity. Conversely, nursing homes that provided health-related services as well as skilled nursing services estimated a greater percent of residents with full capacity, and lower percent of residents with no capacity. This is expected, since residents who receive health-related services are, as a rule, not as ill as those who receive skilled nursing care. The estimates did not vary greatly with the sponsorship or hospital affiliation of the respondent facility.

#### **TABLE D—Residents Adjudicated Incompetent**

A judicial proceeding is the only generally available and legally recognized process to determine that a patient lacks capacity to make health care decisions, and to empower another to make those decisions on the patient's behalf. Nevertheless, the questionnaire responses reveal that exceedingly few nursing home residents are adjudicated incompetent. This is particularly striking in light of the large percentage of residents who lack decision-making capacity (see Table C) and for whom health care decisions must be made.

It is likely that the discrepancy between the small number of residents who have been adjudicated incompetent and the high percentage of residents who lack capacity reflects the cumbersome and costly nature of the judicial process.

#### **TABLE E—Facility Responses to Living Wills**

Currently, there is no legislation in New York State that expressly authorizes the use of living wills and requires facilities to honor the wishes expressed in them. There is, however, case law that recognizes the lawfulness of withholding or withdrawing life-sustaining treatment when there is clear and convincing evidence of the patient's desire to forego treatment.

Against this legal background, the Task Force wanted to understand how hospitals and nursing homes respond to wishes expressed in living wills. The responses fell into four general categories: (1) Yes, will honor living will; (2) No, will not honor living will; (3) Will honor living will under some circumstances; and (4) No policy.



Sixteen percent of the hospitals indicate that, in general, they will honor living wills, 45% will honor them under some circumstances; 29% will not honor them, and 10% have no policy. Thus, a person who simply completes a living will without first ascertaining the hospital's (and physician's) policy has little assurance that the wishes expressed in that document will be honored.

Tertiary hospitals are significantly more likely to give effect to a living will, at least conditionally, than community hospitals. Surprisingly perhaps, hospitals affiliated with medical schools are less likely to honor living wills than those that are not affiliated.

The responses from hospitals in different geographic regions reflected significant regional variation. Hospitals in the Northeastern part of the State, followed by those in Central New York, are the most receptive to living wills; hospitals on Long Island and, to a lesser extent, in New York City and the Northern Metropolitan area are more apt to reject the documents outright.

The percentage of hospitals that will honor a living will in general or under certain circumstances is higher than the total percentage for nursing homes. (Compare Tables E-1 and E-2). Moreover, nursing homes are far more apt to have no policy on this issue.

Interestingly, smaller nursing homes are more willing to honor living wills than larger ones, voluntary nursing homes are more accepting than proprietary or public nursing homes, and hospital-based homes are more accepting than those that are not hospital-based. It is also notable that public nursing homes are far more likely to have no policy on living wills than voluntary or proprietary nursing homes.

In the final analysis, the responses indicate that nursing homes, like hospitals, do not generally regard living wills as binding directives of a patient's treatment wishes.

#### **TABLE F—Conditions for Honoring Living Wills**

The questionnaire asked hospitals and nursing homes to indicate which of four specified conditions must be met before a living will is honored at their facility. The question was directed primarily toward those facilities that had previously stated that they would honor living wills "under some circumstances." However, many facilities that stated that, in general, they "would honor" or "would not honor" living wills also responded to this question.

Hospitals and nursing homes gave remarkably similar responses. Approximately two thirds of the respondents stated that the patient must affirm the wishes expressed in the living will upon or during hospitalization. That condition, however, seriously undermines the usefulness of living wills since it prevents persons from making their plans in advance of hospitalization.

The majority of respondents also stated that they would only honor a living will if the attending physician and patient's family did not object. While the desire for a consensus in these difficult matters is understandable, this policy nevertheless undermines patient autonomy: it affords the patient's physicians and family a veto over the patient's treatment decision—a veto that is not supported by New York law.

The final condition with significant support—from 34% of the hospital respondents and 38% of the nursing home respondents—is a requirement that the living will specify the particular treatment to be withheld or withdrawn. This condition reflects a problem inherent in the use of living wills—health care professionals are understandably reluctant to withdraw treatment based upon instructions that may be vague, ambiguous, or otherwise difficult to apply to the circumstances at hand. As discussed in Chapter IV, this difficulty may be avoided by appointing a surrogate or "agent" to make health care decisions.

#### **TABLE G—Reasons for Not Honoring Living Wills**

Hospitals (but not nursing homes) that previously stated that they would not honor living wills were asked to explain why they would not do so. Ninety-one percent of the hospitals responded, in substance, that they do not honor living wills because New York State does not recognize the validity of such documents. The remaining 9% included such responses as "advice of house counsel," or "law unclear." In fact, as discussed in the report, there is clear support under New York case law for implementing a patient's wishes expressed in a living will.

### **TABLE H—Facility Responses to Durable Powers of Attorney**

Hospitals and nursing homes were asked to state whether they would honor durable powers of attorney for health care for decisions about life-sustaining treatment. The overall responses of hospitals and nursing homes were quite similar: 46% of the hospitals and 52% of the nursing homes stated that they would not honor durable powers of attorney for such decisions; 39% of the hospitals and 41% of the nursing homes stated that they would honor them. Given the limited legal support for reliance on a durable power under existing New York law, the acceptance of the documents is high.

Community hospitals are more likely to honor durable powers than tertiary hospitals, and hospitals with less than 100 beds are more likely to honor the documents than larger hospitals. Hospitals affiliated with medical schools are considerably less willing to honor durable powers than those not affiliated.

A geographic analysis of the responses reveals differences similar to those observed with respect to living wills: hospitals from upstate regions are significantly more receptive toward durable powers than hospitals in the downstate regions.

Among nursing homes, there was no clear difference in responses from facilities that provide and those that do not provide health-related services. Nor was there any clear difference based on facility size. Voluntary nursing homes are more willing to honor durable powers than proprietary homes, a finding that is consistent with their responses about living wills.

### **TABLE I—Reasons for Not Honoring Durable Powers**

The questionnaire asked hospitals that do not honor durable powers to explain their reason for not doing so. Forty-four percent answered, in substance, that New York State does not recognize their validity, while 23% answered that the use of durable powers was a new issue, the legality of which was unclear.

Ironically, far more hospitals are convinced that living wills are not lawful (91%) than believe that durable powers are unlawful (44%). In fact, as discussed in Chapter IV of the Report, there is far greater legal support for living wills than for durable powers under New York law.

**Survey of  
Hospitals and Nursing Homes  
in New York State**

**Statistical Tables**

## TABLE A—PROFILE OF RESPONDENTS

**Table A-1**  
**Profile of Hospital Respondents**

Response Rate	Type of Hospital	Size by Number of Certified Beds	Region	Medical School Affiliation
239 Questionnaires	83% Community Hospital	24% Less than 100 beds <sup>2</sup>	11% Nassau/Suffolk	40% Med. school affiliated 60%
139 Responses	17 % Tertiary Hospital <sup>2</sup>	32% 100-250 beds	22 % Greater New York	Not med. school affiliated
58% Overall Response Rate <sup>1</sup>		28% 250-500 beds	11% Northern Metropolitan	
		15% More than 500 beds	17% Northeastern	
			17% Central	
			10% Rochester 13%	

<sup>1</sup> The response rate for a particular question may be lower.

<sup>2</sup> Includes two Speciality Hospitals.

<sup>2</sup> Percentages will total from 99% to 101% due to rounding off of constituent percentages.

**Table A-2**  
**Profile of Nursing Home Respondents**

Response Rate	Type of Nursing Home	Size by Number of Certified Beds	Sponsorship	Hospital-based
622 Questionnaires	56% Skilled nursing facility	12% Less Than 50 beds	49% Voluntary	16% Hospital-based
196 Responses	44% Combined SNF and HRF	22% 50-99 beds	38% Proprietary	84% Not based
32 % Overall		37% 100-199 brds	12% Public/Gov	
		29% More than 200 beds		

**TABLE B—WRITTEN GUIDELINES FOR DETERMINING CAPACITY**

*Question:* "Does your hospital/nursing home have written guidelines for the procedure to determine capacity?"

**Table B-1**  
**Hospitals: Written Guidelines for Determining Capacity**

All								
Respondents	Type of Hospital		No. of Certified Beds				Region	Affiliation
	Nass/ Grtr		Nrth NE	Ctrl	Rch	Buf		
	Comm.	Tert.	< 100	100-250	250-500	>500		
[136]	[115]	[21]	[33]	[45]	[38]	[20]		
29%	28%	38%	21%	20%	39%	45%		
71%	72%	62%	79%	80%	61%	55%		

**Table B-2**  
**Nursing Homes: Written Guidelines for Determining Capacity**

	All Respondents	Type of Nursing Home		No. of Certified Beds				Sponsorship			Hospital-based	
		Skilled Nursing Facility [105]	Combined Facility [84]	<50 [22]	50-99 [41]	100-199 [71]	>200 [55]	Voluntary [93]	Proprietary [69]	Public [23]	Hospital Based [31]	Not Hosp. Based [158]
	[196]											
Yes	13%	11%	14%	9%	17%	13%	11%	13%	13%	9%	23%	11%
No	85%	87%	82%	91%	80%	85%	85%	83%	87%	91%	74%	87%
In Progress <sup>4</sup>	3%	2%	4%	0%	2%	3%	4%	4%	0%	0%	3%	3%

**TABLE C—ESTIMATE OF PATIENT CAPACITY LEVEL**  
[Nursing Homes Only]

*Question:* “Please estimate the percentage of residents in your nursing home who currently fall into the following categories: (a) full decision making capacity; (b) capacity to make some health care decisions; (c) lacks capacity to make any health care decisions.”

Average of	All Respondents	Type of Nursing Home		No. of Certified Beds				Sponsorship			Hospital-basal	
		Skilled Nursing Facility [101]	Combined Facility [74]	<50 [39]	50-99 [19]	100-199 [64]	>200 [53]	Voluntary [66]	Proprietary [86] [66]	Public [18]	Hospital Based [24]	Not Hasp. Based [151]
	[175]											
Full Capacity	26%	19%	36%	18%	25%	25%	31%	28%	23%	25%	24%	27%
Part Capacity	26%	27%	25%	27%	26%	26%	26%	26%	26%	24%	24%	27%
No Capacity	47%	54%	39%	54%	49%	49%	42%	45%	51%	50%	52%	47%

<sup>4</sup> Not one of the choices provided in the questionnaire.

**TABLE D—RESIDENTS ADJUDICATED INCOMPETENT**  
(Nursing Homes Only)

*Question:* ‘How many residents in your nursing home had been adjudicated incompetent as of October 1, 1986?’”

	Average of All Responses	Type of Nursing Home		No. of Certified Beds			Sponsorship			Hospital-based	
		Skilled Nursing Facility	Combined Facility	<50	50-99	100-199 >200	Vbluntary	Proprietary	Public	Hospital Based	Not Hosp. Based
		[95]	[72]	[63]	[47]	[20][37]	[82]	[60]	[20]	[30]	[137]
		[167]									
Average Number of Residents Adjudicated Incompetent	2.4	2.3	<b>2.6</b>	1.4	2.4	2.4	<b>2.2</b>		1.8	1.7	2.6



# TABLE E-FACILITY RESPONSES TO LIVING WILLS

Question: "In general, how does your hospital/nursing home respond to wishes expressed in a living will?"<sup>1</sup>

Table E-1 Hospitals: Response to Living Wills

All	Respondents	Type of Hospital		No. of Certified Beds				Med. School Region						Affil.		
	[135]	Comm. Tert. [112]	Tert. [23]	<10 0 [33]	100-250 [38]	250-500 [44]	>500 [20]	Mass/ Suffk [16]	Grtr NY [27]	Nrtb Mtr [15]	NE NY (221)	Ctrl NY [23]	Rch sir [Mi]	Buf falo (181)	Mil. [54]	Not Affil. [81]
Yes, will honor	16%	16%	17%	18%	16%	13%	20%	0%	22%	13%	23%	22%	0%	22%	11%	20%
No, will not honor	29%	30%	22%	18%	30%	34%	35%	50%	41%	40%	18%	22%	14%	17%	39%	22%
Will honor under some circumstances	45%	43%	57%	39%	50%	47%	40%	50%	30%	33%	50%	48%	71%	44%	44%	46%
No policy	10%	11%	4%	24%	5%	5%	5%	0%	7%	13%	9%	9%	14%	17%	6%	12%

<sup>1</sup> The questionnaire did not provide response choices. Responses were analyzed and assigned to one of the Sour categories set forth above.

**Table E-2**  
**Nursing Homes: Response to Living Wills**

TABLE F—CONDITIONS FOR HONORING LIVING WILLS

Question: “Please check the appropriate responses) to the following statement: Living Wills are not honored unless...” (4 choices provided).

Table F-1 Hospitals: Conditions for Honoring living Wills		[74]
All Respondents	The living will specifies the particular treatments to be withheld or withdrawn	34%
	Family members do not object to wishes expressed in the living will	57%
	The attending physician does not object to wishes expressed in the living will	64%
	The patient affirms wishes expressed in the living will upon or during hospitalization	69%

**Table F-2 Nursing Homes: Conditions for  
Honoring Living Wills**

	All Respondents [101]
The living will specifies the particular treatments to be withheld or withdrawn	38%
Family members do not object to wishes expressed in the living will	53%
The attending physician does not object to wishes expressed in the living will	68%
The patient affirms wishes expressed in the living will upon or during hospitalization	61%

Question: "If your hospital does not honor living wills, why not?"

	All Respondents [34]	
New York State does not recognize their validity	91	%
Other	9%	

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<sup>5</sup> E.g., "advice of house counsel," "does not apply when patient is incompetent," "law unclear."

**TABLE H—FACILITY RESPONSES TO DURABLE POWERS OF ATTORNEY**

*Question:* “Does your hospital/nursing home honor durable powers of attorney for decisions regarding the withholding or withdrawal of life- sustaining or life-saving medical treatment?”

**Table H-1 Hospitals: Responses to Durable Powers of Attorney**

							Nass/ Suffk [16]	Grtr NY [27]	Nrth Mtr [15]	NE NY [19]	Ctrl NY [22]	Rch str [13]	Buf falo [17]	Affil. [53]	Not [76]
[129]	Comm. [108]	Tert. [21]	<100 [30]	100-250 [42]	250-500 [78]	>500 [20]									
39%	40%	33%	67%	29%	35%	25%	19%	26%	20%	47%	55%	54%	53%	28%	46%
46%	45%	48%	23%	55%	49%	55%	44%	63%	60%	47%	36%	31%	29%	53%	41%
16%	15%	19%	10%	17%	16%	20%	38%	11%	20%	5%	9%	15%	18%	19%	13%

**TABLE I—REASONS FOR NOT HONORING DURABLE POWERS OF ATTORNEY  
[Hospitals Only]**

**Table H-2 Nursing Homes: Responses to Durable Powers of Attorney**

All Respondents	Type of Nursing Home	No. of Certified Beds	Sponsorship	Hospital-based	
	Skilled Nursing Combined			Hospital	NotHasp.



	[174]	Facility [100]	Facility [74]	<50 [22]	50-99 [37]	100-199 [47]	>200 [47]	Vblntry [82]	Proptrtry [64]	Public [22]	Based [311]	Based [142]	EY
Yes, will honor	41%	41%	42%	45%	51%	34%	43%	51%	33%	27%	48%	40%	
No, will not honor	52%	51%	54%	50%	46%	57%	51%	41%	64%	64%	39%	55%	
No policy <sup>6</sup>	6%	8%	4%	5%	3%	9%	6%	7%	3%	9%	13%	5%	

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<sup>6</sup> Not one of the choices provided in the questionnaire. Includes “under discussion,” “no cases so far” and "handled on a case-by-case basis.”

**TABLE I—REASONS FOR NOT HONORING DURABLE POWERS OF ATTORNEY**  
*Question: "If your hospital does not honor durable powers of attorney, why not?"*  
**[Hospitals Only]**

	<b>All Respondents</b> [39]
New York State does not recognize their validity	44%
New issue; legality unclear	23%
Does not apply when patient is incompetent	13%
Durable powers are only for financial matters	8%
Advice of counsel	8%
Family participation is required	5%

**TABLE I—REASONS FOR NOT HONORING DURABLE POWERS OF ATTORNEY  
[Hospitals Only]**

**TABLE I—REASONS FOR NOT HONORING DURABLE POWERS OF ATTORNEY  
[Hospitals Only]**

**TABLE I—REASONS FOR NOT HONORING DURABLE POWERS OF ATTORNEY  
[Hospitals Only]**

**TABLE I—REASONS FOR NOT HONORING DURABLE POWERS OF ATTORNEY  
[Hospitals Only]**



**TABLE I—REASONS FOR NOT HONORING DURABLE POWERS OF ATTORNEY  
[Hospitals Only]**



**TABLE I—REASONS FOR NOT HONORING DURABLE POWERS OF ATTORNEY  
[Hospitals Only]**

**TABLE I—REASONS FOR NOT HONORING DURABLE POWERS OF ATTORNEY  
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